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The Lived Experience of Parental Bereavement

by

Christine Yvonne Denhup

Submitted in partial fulfillment of the requirements for the degree

Doctor of Philosophy

College of Nursing

Seton Hall University

May 2014

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ACKNOWLEDGEMENTS

I extend heartfelt appreciation to my Dissertation Chair, Dr. Judith Lothian, Ph.D., R.N., and Committee for their support, encouragement, and expert guidance throughout this research process. Upholding a standard of excellence, they dedicated countless hours, offered valued input, and engaged in helpful discussions which served to enrich this dissertation. For all of their contributions, I am very grateful.

I wish to thank Sigma Theta Tau International Honor Society of Nursing, Gamma Nu Chapter for their foresight in recognizing the importance of this dissertation in its very early stages. Gamma Nu bestowed upon me the 2011 Gamma Nu Research Grant in recognition of the quality of my dissertation proposal. This award helped to fund a portion of incurred expenses of this dissertation. For this, I am both grateful and honored.

I am very thankful for the many support group informants for the multitude of ways in which they facilitated this study to come to fruition. I extend my deepest gratitude to each of the parents who partnered with me to complete this study. Through their stories, nursing gains a deeper understanding of the meaning of the lived experience of parental bereavement which, in turn, will improve care for parents who experience the death of a child in the future.

Most especially, I am thankful for the loving support and encouragement of my family. My family has sustained me throughout my doctoral education journey. I could not have completed this journey without them.

DEDICATION

I dedicate this work to my Mom, Elaine Denhup, forever my guiding light who believed in the value of education, the importance of helping others, and the love of family.

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ABSTRACT

The purpose of this manuscript is to present a Heideggerian hermeneutic phenomenological nursing research study on the phenomenon of parental bereavement. The aim of this study is to describe the lived experience of bereaved mothers and fathers who have experienced the death of a child due to cancer. Van Manen's (1997) method guided this qualitative inquiry. New knowledge describing the meaning of the lived experience of parental bereavement promotes a better understanding of the phenomenon from the perspective of parents, fills a significant gap in the literature, and informs nursing research, education, and practice.

Keywords: parental bereavement, child death, hermeneutic phenomenology, Van Manen's methodology

Chapter I

INTRODUCTION

THE LIVED EXPERIENCE OF PARENTAL BEREAVEMENT

Phenomenon of Interest

The death of a child is life's most difficult, intense, and traumatic experience regardless of the cause (Foster, Lafond, Reggio, & Hinds, 2010; Himmelstein, Hilden, Boldt, & Weissman, 2004; James & Johnson, 1997; Rando, 1985; Sanders, 1980; Wilson, 1988). The Centers for Disease Control and Prevention (CDC) reports that 45, 068 children and adolescents, 19 years of age or less, died in the United States during 2010 (Murphy, Xu, & Kochanek, 2013) leaving tens of thousands of parents to experience bereavement.

Bereavement, as defined in the Institute of Medicine report, *When children die: Improving palliative and end-of-life care for children and their families*, is "a broad term that encompasses the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one" (Christ, Bonanno, Malkinson, & Rubin, 2003, p. 554). Bereavement is considered to be a complex, dynamic, nonlinear process (Christ *et al.*, 2003) that includes "internal adaptation of individual family members, their mourning processes, expressions, and experiences of grief; and changes in external living arrangements,

relationships and circumstances” (Christ *et al.*, 2003, p. 554). The parental bereavement experience has relevance for nursing and merits deep understanding.

Relevance for Nursing

It has been reported that bereaved parents are at high risk for serious negative health outcomes, including posttraumatic stress disorder symptoms (Murphy, Johnson, & Lohan, 2002), guilt, anger, depression, migraine headaches, pain, feelings of chest pressure and arrhythmias (Aho, Tarkka, Åstedt-Kurki, & Kaunonen, 2006). Furthermore, a higher mortality rate has been noted among bereaved parents than among non-bereaved parents (Li, Precht, Mortensen, & Olsen, 2003). Given the seriousness of these health risks, there is no doubt then that bereaved parents are in great need of the most compassionate and knowledgeable care that professional nurses can provide. Therefore, nurses must possess deep understanding of the parental bereavement experience if they are to provide optimal care.

Problem and Justification

While studies describing consequences of parental bereavement (Aho *et al.*, 2006; Alderman, Chisholm, Denmark, & Salbod, 1998; Barr & Cacciatore, 2008; Li *et al.*, 2003; Murphy, Johnson, Chung, & Beaton, 2003; Murphy *et al.*, 2002; Rogers, Floyd, Seltzer, Greenberg, & Hong 2008), evaluation of bereavement interventions (Davies, 2007; Heiney, Wells & Gunn, 1993; Schut & Stroebe, 2005), and

explanations of bereavement's conceptual underpinnings (Aho et al., 2006; Bunkers, 2006; Christ *et al.*, 2003; Cimete & Kuguoglu, 2006; Corless, 2010; Davies & Jin, 2006; Eakes, Burke, & Hainsworth, 1998; Field, 2006; Field, 2008; Packman, Horsley, Davies, & Kramer, 2006; Parse, 1997; Pilkington, 2006; Robinson & McKenna, 1998; Teel, 1991) can be found in the literature, few researchers have studied the needs of bereaved parents from their personal perspectives. Studies that do exist are limited particularly in regard to mixed sample selection and generalizability of findings. Li, Chan, and Lee (2002) used a mixed-method approach to explore nurse actions that bereaved families perceived as helpful and to examine the relationships between and among demographic variables and bereaved families' perception of helpfulness of the nurse actions. Of the convenience sample of 76 Cantonese-speaking, Chinese adults who had experienced the sudden death of a family member, only 19% were parents of a child who had died of sudden causes. Because over 80% of data were not based on experiences of parents, it is difficult to delineate which findings, if any, specifically relate to bereaved parents. D'Agostino, Berlin-Romalis, Jovcevska, and Barrera (2008) qualitatively studied bereavement-related needs among a convenience sample of Canadian parents, including five mothers and two fathers, who participated in a focus group moderated by a social worker and psychologist. Although the overall small sample size is consistent with samples found in qualitative studies, fathers were underrepresented in comparison to mothers who participated.

Although studies offer some initial insight into parental bereavement, the literature is silent on the meaning of parental bereavement as it is experienced by parents living in the United States who have experienced the death of a young child due to cancer. In addition, there is a paucity of literature concerning fathers' parental bereavement experience. Although significant progress has been made in reducing childhood cancer mortality rates, cancer remains the second leading cause of death in children and is estimated to have caused 1,340 deaths in children less than 14 years of age in 2012 (American Cancer Society, 2012). Therefore, better understanding of the bereavement experience among parents of children with cancer is merited.

Aim of the Study

The aim of this study is to describe the lived experience of bereaved mothers and fathers who have experienced the death of a child due to cancer.

Research Question and Design

Phenomenology will be used to answer the research question, "What is the lived experience of bereaved mothers and fathers who have experienced the death of a child due to cancer?" Phenomenology is the study of the meaning of a phenomenon as it is experienced (Munhall, 2007). According to Merlau-Ponty (1962), what an experience means to a person will influence the person's perception of that experience; therefore, it is important to understand the meaning of parental

bereavement, which in turn will expand nursing's understanding of parental perceptions of their experience.

Researcher's Perspective

From a worldview perspective, it is the interpretation of the bereavement experience from the perspective of bereaved parents that is critical – the bereavement experience as parents perceive it must be better understood (Munhall, 2007). My worldview is consistent with this viewpoint. As a qualitative researcher, it is important that I reflect on my experiential knowledge. As a practicing licensed registered nurse and advanced practice registered nurse who was nationally certified as a Certified Pediatric Oncology Nurse (CPON©) by the Oncology Nursing Certification Corporation for many years and currently is recognized by the American Association of Colleges of Nursing as a End-of-Life Nursing Education Consortium – Pediatric Palliative Care (ELNEC-PPC©) national trainer, I bring over 22 years of experience caring for children and their families to this current research which has shaped my worldview. My knowledge has been nurtured in numerous ways throughout my nursing career, including: a) seven years in the role of a registered nurse who provided direct care for children before, during, and after their death and who partnered with a fellow nurse colleague to create the first unit-based bereavement program within one children's hospital; b) ten years in the role of a pediatric clinical nurse specialist who contributed to the advancement of nursing care of children and their families through the creation and implementation of evidence -based clinical

practice guidelines; and c) five years as an academic nurse educator who is passionately engaged in the education of the future generation of nurses. In clinical practice, I have personally felt uncertain about how best to help families after their child died. Many of my nursing colleagues have verbally shared similar feelings. In nursing education, I have observed deficiencies in pediatric palliative and end-of-life care content in nursing curricula. Most strikingly, bereaved parents themselves for whom I cared throughout my years in practice have influenced my worldview.

In my past practice, I have had many conversations and received written correspondence from bereaved parents of children for whom I cared. The examples that follow are just a sampling of communications that I have had in my past practice with bereaved parents. Some bereaved parents articulated how important it is that nurses recognize their experience. For example, bereaved parents have said: a) “at a time when parents are least able to ask for the help they need, you are reaching out and making the effort to help us through a difficult time” by providing written and telephone follow-up, written literature and book lists on the grieving process, and information on available support groups; b) there is a need for “the development of more comprehensive hospital wide programs” to support families; and c) “it is important to most families to receive some acknowledgement of their child’s life and death” from the hospital. Other parents have commented on the importance of special relationships that were formed. One parent wrote “if it wasn’t for the time you spent with all of us, we’d never have gotten through this. I’ve thanked God for that over and

over! Remember the middle of the night when they looked for you for about 45 minutes and you were in our room listening to me? I'll never forget the support we all got". Another parent adds "it is still hard to believe that Sally was so ill and her death over a year ago. I cannot think about that for very long. I still have days when I simply have to grieve more intensely..so I do..& usually feel better and closer to Sally for it". Another parent adds, "we have been through a difficult time together and I feel a bond with you that can not exist even in friendships of a lifetime". Finally, a father writes "From our first night there until her last minutes, you not only took care of her in every sense of the word but you took care of my wife, myself, her brother, and my family. You gave us constant support for a very long 8 months. You let me vent when I needed to, cry when we all needed to, talk about her or not about her or something so far removed from the hospital, or not to talk at all – it was all needed."

The above communications which I received from bereaved parents in my past practice have significantly shaped my worldview. I believe that if nurses are to provide optimal care for bereaved parents, they must first have a deep understanding of the meaning of parental bereavement. To gain deep understanding, it is my worldview that nurse researchers must go directly to the experts – those individuals who are living the experience of bereavement, the bereaved parents themselves.

Chapter II

REVIEW OF LITERATURE

Evolution of Bereavement Theories

Bereavement theories have evolved over the years. The beginnings of bereavement theory can be traced back to the mid 20th century and are grounded in the psychoanalytic tradition, commencing with Freud's seminal work "Mourning and Melancholia" (1917/1957). Freud postulated that the most crucial task for bereaved individuals was to work through the loss and detach mentally and emotionally from the deceased, withdrawing libido, in order to refocus attention on another and thus achieve successful adaptation and resolution. Detachment from the deceased, as Freud believed, was the desired task of bereavement. However, Davies (2004) found in a review of literature on parental grief that although Freud had advocated for absolute detachment, this was far from his personal experience with the death of his own daughter, Sophie. Evidence of this is found in a personal letter Freud wrote to a friend whose own child had died nine years after Sophie's death:

Although we know that after such a loss the acute stage of mourning will subside, we also know that we shall remain inconsolable and will never find a substitute...actually, this is how it should be. It is the only way of perpetuating that love which we do not wish to relinquish. (Freud, 1929, cited in Davies, 2004, p. 507-508).

Freud's personal bereavement experience with the death of his child is a direct contradiction of the theoretical belief that detaching from and disconnecting bonds to the deceased is required. This is a significant theoretical paradox, yet for many years this conviction remained at the center of subsequent stage theories of bereavement. Stage theories postulated that bereaved individuals progress in a linear fashion through sequential stages to achieve the optimal goals of recovery from their loss, reorganization of their life back to normal, and acceptance of their loved one's death (Bowlby & Parkes, 1970; Kübler-Ross, 1969).

The literature provides evidence that a major shift in the theoretical underpinnings of bereavement is occurring. Instead of holding tight to the linear model of a time-bound, step-wise resolution of grief associated with the bereavement experience, scholars have raised the idea that detachment and resolution are not required bereavement outcomes, but rather that grief and continued bonds with the deceased may continue throughout the course of the bereaved person's life without ever having complete closure of the bereavement experience (Burke, Eakes, & Hainsworth, 1999; Eakes, Burke, & Hainsworth, 1999; Field, 2006; Kübler-Ross & Kessler, 2005; McClowry, Davies, May, Kulenkamp, & Martinson, 1987; Packman *et al.*, 2006; Rando, 1985; Rubin, 1999; Woodgate, 2006).

Related Concepts

Living in a world without closure. The concept of *living in a world without closure* appears in the parental bereavement literature. Woodgate (2006) conducted a

phenomenological study to explore parents' lived experience of transitioning through the death of a child due to illness. The illness-related causes of death included multiple birth defects, congenital heart defects, sudden infant death syndrome, cancer, cystic fibrosis, cerebral palsy, and septicemia. At the time of their death, the children ranged in age from three days to 28 years. The time since the child's death ranged from seven months to 18 years. Twenty-eight Canadian parents (17 mothers, 11 fathers) from 18 families were interviewed and asked to describe their experience by talking about what life was like before, during and after their child's death. Four main themes emerged: (a) *keeping the memories alive* (memories of their child helped parents to maintain a connection with their child); (b) *being a good parent* (parents valued knowing that they did everything possible for their child to have a happy life with minimal suffering); (c) *being there at my child's death* (being present to help their child at the time of death was important for parents); and (d) *being there for me after my child dies* (parents valued the presence of family, friends, and their child's health care providers in the months and years following the death). These four themes characterize the concept of living in a world without closure for parents who have experienced the death of a child. Notably, the findings suggest that parents did not want to experience closure in their transitioning. As Woodgate (2006) explains, "living without closure was not viewed by the parents as a negative or positive phenomenon, but just something that they would live with for the rest of their lives" (p. 78). The findings reflect the ongoing evolution occurring in bereavement theory

and recognize that parental bereavement is not time-limited, but rather a process that is reflective of a continual, ongoing phenomenon. While the findings illuminate the lived experience of mainly Canadian mothers who had a child die from illness, it is unknown if this lived experience is the same or different for bereaved mothers and fathers from other countries; thus, there is a need for further study in order to advance nursing knowledge and understanding.

Lived experience of grieving. Pilkington (1993) used Parse's (1987) method in a phenomenological exploration of the lived experience of grieving in five mothers who lost their babies at birth. From the core concepts extracted from participants' dialogue, a structure of the mothers' lived experience was formulated as, "anguished suffering in devastating void amidst consoling movements away from and together with the lost one and others while confidently moving beyond personal doubts" (Pilkington, 1993, p. 132). Through heuristic interpretation, this structure was woven with Parse's *humanbecoming* theory (Parse, 2007), the principles of which are: a) people create meaning in their lives; b) people live in rhythmical patterns; and c) people *cotranscend*, or move through their experiences, to transform their realities (Parse, 2007). This enabled Pilkington (1993) to explain the lived experience of grieving among mothers whose babies had died at birth: "the lived experience of grieving the loss of an important other is a pronounced agony with intense yearning for the cherished other through engaging-disengaging with the absent presence and others while mobilizing energies toward uncertain possibilities" and "is valuing the

connecting-separating in transforming” (p. 132). While the findings advance understanding of the lived experience of grieving among mothers and validate the use of Parse’s method and theory in scientific inquiry of universally lived experiences, they do not advance understanding of the lived experience of parental bereavement.

Meaning-making. There is evidence in the literature that meaning-making is important in parental bereavement. Wheeler (2001) designed a descriptive, qualitative study to explore the concept of the search for meaning in parental bereavement. The sample consisted of 176 bereaved parents who were recruited from The Compassionate Friends Network and who represented four geographic regions of the United States. The sample majority was Caucasian, Protestant mothers who graduated from high school and had an annual income of more than \$25,000. Their children were between the ages of 0-48 years and who died anywhere between one month to 40 years prior to the study. Accidents accounted for the majority of child deaths, followed by illness, murder, and suicide. Parents were asked to complete a questionnaire that included qualitative questions related to their experience of their child’s death over time and the meaning of their life since their child’s death. Findings were analyzed and sorted into five major categories which emerged from the parents responses. Several subcategories emerged from the question about their experience of the death over time. Parents’ initial responses at the time of their child’s death consisted of the inability to accept the reality of the child’s death; emotional reactions, including anger, bitterness, pain, fear, and guilt; and a preoccupation with

the child. Parents' current responses at the time the study was conducted included continued questioning as to how the death happened and could it have been prevented, an acceptance and resignation that the death occurred, and an inability to accept that the death had to be. Several areas about their child's death experience stood out for parents as having the most meaning and significance. First was the loss itself, whereby parents felt something would be missing from their lives forever, as well as feelings of grief, frustration, guilt, and regret. Second, the child, including the child's life, death and keeping memories alive, was an emerging theme that held particular significance for parents. A third area of significance was maintaining a connection with people, including surviving children, children born since the death, spouse, grandchildren, family members, friends, and other bereaved parents. A fourth area of significance was the positive outcomes of their bereavement experience, including a new appreciation for life, deeper religious and spiritual understanding, becoming a better person, and gaining the knowledge that they are able to survive a situation that they perceive as unbearable.

In response to the question about meaning of the parent's life since the child's death, Wheeler (2001) found that 90% of parents believed that something had given their life meaning, whereas 10% indicated that nothing had given their life meaning. Of the 90% who indicated that something had given their life meaning, the following themes emerged: (a) having contact with people; (b) engaging in helping, work, and

relaxing activities; (c) maintaining connections with their dead child; and (d) personal growth.

Findings from Wheeler's (2001) study offer evidence that meaning-making is an important aspect of parental bereavement for the sample of Caucasian, Protestant mothers in the United States. A need for a more holistic understanding of the phenomenon of parental bereavement from the perspective of both mothers and fathers from other ethnic and cultural backgrounds remains. Further, since the sample inclusion criteria were so broad, including parents of children who died between the ages of 0-48 years and whose causes of death were primarily accidents and without warning, the lived experience of parents who have suffered the death of a young child due to a specific illness remains unknown.

In summary, the literature illustrates an ongoing evolution of bereavement theories and emergence of concepts related to parents' experience following the death of a child, such as living in a world without closure, grieving, and meaning-making. In spite of growing insight about parental bereavement, the literature remains silent on the meaning of parental bereavement as it is experienced by fathers and mothers who have experienced the death of a young child due to cancer. This phenomenological study is needed to address this gap.

Chapter III

METHODOLOGY

Phenomenology

Phenomenology is the study of the meaning of a phenomenon as it is experienced (Munhall, 2007). Meaning is important to understand, for it is meaning which creates the ways in which individuals perceive their experiences (Merlau-Ponty, 1962). There is a need to better understand the parental bereavement experience as parents themselves perceive it. Hence, phenomenology is the best qualitative approach to guide this inquiry.

Heideggerian hermeneutic phenomenology. Heideggerian hermeneutic phenomenology, which seeks to discover and interpret how individuals see and understand their experiences (Gerow et al., 2010; Heidegger, 1962; Polkinghorne, 1989), provides the philosophical underpinnings of this study. Heidegger was a German philosopher who is considered to be the founder of hermeneutic phenomenology (Annells, 1996). Heidegger's (1962) definition of phenomenology is "to the things themselves!" (pg. 50); whereby, *the things* have been conceptualized as lived experiences (McConnell-Henry, Chapman, & Francis (2009). Heidegger's (1962) definition of hermeneutic is the "business of interpreting" (pg. 62).

Heidegger (1962) believed that both description and interpretation are necessary in order to understand the meaning of lived experiences. Carman (2008)

gives voice to Heidegger's view that phenomenology describes and interprets "the *being* of things, the existence of ourselves and the world around us" (pg. xviii).

According to Heidegger (1962), *Being* is all that makes entities what they are. Central to Heidegger's philosophy is the concept of *Dasein*, a Greek term used in reference to the Being of persons (Heidegger, 1962). *Dasein* has been conceptualized as "the situated meaning of a human in the world" (Annells, 1996, p. 706). Heidegger (1962) believed that phenomenology allows all that manifests "*explicitly*" (pg. 59) and what "*lies hidden*" (pg. 59) in *Dasein* to be seen. Heidegger (1962) also spoke to the concept of *temporality*, which has been explained as "all possibilities of being which make sense to us in terms of time – past, present, and future" (Earle, 2010). This means that a person's past experiences influence the present and the future (McConnell-Henry *et al.*, 2009).

Heidegger (1962) felt that understanding always comes with presuppositions. Heidegger (1962) presented the concept of the *hermeneutic circle*, whereby understanding arises in a circular fashion in which a researcher brings her own pre-understandings, or *fore-conception*, about a given phenomenon to the research; seeks to understand the phenomenon by first making pre-understandings known; and then, by studying the whole and the parts of a phenomenon, moves towards an interpretive understanding of lived experience (Earle, 2010; Koch, 1995; McConnell-Henry *et al.*, 2009).

Heidegger (1962) does not propose any specific methodology for conducting phenomenological research. Rather, he simply offers a philosophical perspective from which research methods could be derived. Therefore, researchers must turn to other scholars who have developed methods framed by Heideggerian philosophy. Van Manen (1997) is one such scholar.

Van Manen's method. Van Manen (1997) is a Canadian scholar who was greatly influenced by Heideggerian philosophy. Van Manen (1997) concurs with Heidegger's view that interpretation is critically important in understanding the meaning of lived experiences. Van Manen (1997) offers an approach to aid researchers in their efforts to interpret the meaning of lived experiences. Van Manen's (1997) method, which consists of six research activities, informed data collection and analysis and ultimately uncovered the full meaning of the lived experience of parental bereavement.

Specifically, data collection and analysis was guided by the following activities outlined in van Manen's (1997) method:

1. *Turn to the nature of lived experience and commit to a concern.* Here, the researcher engages in thoughtfulness and deep questioning to make sense of an aspect of human existence. I committed to a fullness of thought about parental bereavement and studied its *essence*, or description. This ultimately revealed a structure of parental bereavement and allowed me as a researcher to better understand the nature and significance of parental bereavement in a way

previously unknown. As suggested by van Manen (1997), I made my knowledge of parental bereavement explicit by recalling my past experience as a nurse caring for parents whose child had died and by articulating what is known about the phenomenon in the literature to date.

2. *Investigate the experience as it is lived.* The focus here is to understand parental bereavement from the perspective of bereaved parents– the individuals who are living this experience as an integral part of their being-in-the-world. After gaining informed consent, I proceeded with interviews to inquire about participants’ own lived experience of parental bereavement. During conversational interviews, parents were asked, “Please tell me what it has been like for you since your child died”. I did not interject questions, but moved the discussion along with comments such as, “Go on”, “Please say more about what it was like for you”, or “Can you think of anything else that would help me to understand what it has been like for you since your child died?”. Before ending each interview, I asked the parents if there is anything else that they would like to add and for permission to contact them again for any needed clarification. The audio-recorded interviews were conducted privately with each parent on two separate occasions. The sum length of each parent’s interview ranged between 3-5 hours. The aggregate length of all interviews amassed to 23 hours. In-person interviews were completed with three parents who lived within a three hour commute radius. Telephone interviews were

completed with three other parents due to the fact that they lived a significant distance away. Each audio-recorded interview was transcribed, yielding 621 cumulative pages of typed text.

3. *Reflect on essential themes.* A true reflection, according to van Manen (1997), is “a thoughtful, reflective grasping of what it is” (p. 32) that gives parental bereavement its special significance. Reflection helped me to determine what constitutes the nature of parental bereavement. To accomplish this, I utilized three approaches outlined by van Manen (1997) which include a *wholistic reading* approach, a *selective highlighting* approach, and a *detailed line-by-line* approach. All three approaches were used in the analysis of each parent’s transcribed interview text. First, I completed a wholistic reading of the each unabridged text in attempts to gain an overall sense of the fundamental meaning of what each parent was telling me. I formulated one sentence to capture my interpretation of the overall meaning of each parent’s experience. Then I selectively highlighted statements within each parent’s transcribed text that seemed to be particularly revealing about each parent’s experience. Noted as verbatim quotations within this manuscript, these statements provide supportive evidence of emerging themes. When completing the detailed reading approach, I color-coded each sentence of each parent’s transcribed text to determine what each sentence or sentence cluster revealed about the nature of each parent’s experience and made notations in the transcript’s right-hand

margin. This detailed approach helped to uncover numerous categories of information. Van Manen's (1997) approaches offer a multilayered technique that ultimately unveiled essential themes of the lived experience of parental bereavement. It is an iterative process, where the researcher moves from each whole transcribed interview, through selected excerpts and sentences, to emerging themes, back to the whole transcribed interviews, and finally to the creation of a narrative text. This was done for each parent's interview transcript, thus allowing for overarching essential themes to be revealed from the unique essential themes in all the interviews as a whole.

4. *Write and rewrite.* Writing is not the final step of the research process, but rather the culmination of the interpretive analysis in hermeneutic phenomenological research which provides a comprehensive view of the parental bereavement experience. According to van Manen (1997), writing "fixes thought on paper" (p. 125), "mediates reflection and action" (p.124), and "exercises the ability to see" (p. 129). I wrote and rewrote throughout the entire research process and have come to understand exactly what Van Manen means about writing. In my experience of doing this research study, writing became the act of doing. Through the act of writing and rewriting, my interpretive analysis of the meaning of the lived experience of parental bereavement evolved. Writing forced my thoughts about what study participants were telling me down on paper, facilitated my reflection on how to

proceed, and opened my eyes into the lived experiences of participants which allowed me to more clearly see the phenomenon of parental bereavement.

Now, I have a better understanding and appreciation for writing. Writing, in essence, is the doing of hermeneutic phenomenological research.

5. *Maintain a strong and oriented relation.* As a phenomenological researcher, I maintained a strong connection with the phenomenon of parental bereavement during research and reflection. Evidence that I did so is found in the depth and breadth of this written manuscript that offers deep insight into the meaning of the lived experience of parental bereavement.
6. *Balance the research context by considering parts and the whole.* As a phenomenological researcher, I considered the overall study and the significance that all its individual parts played. An openness is needed for this type of research that, according to van Manen (1997), “allows for choosing directions and exploring techniques, procedures, and sources that are not always foreseeable at the outset of a research project” (p. 162). This requires mindfulness and attention to moving between parts and the whole of the findings. Movement between parts and whole provides clarity and helps to reveal the essence of what makes parental bereavement what it is.

Framed by Heidegger’s philosophy and informed by Van Manen’s (1997) method, this phenomenological study presents a possible interpretation of the nature of parental bereavement. Essential aspects of parental bereavement are revealed so

that others may recognize this interpretive description as a possible experience.

Readers will ultimately gain deep understanding of what parental bereavement means.

Protection of Human Subjects

Autonomy and the principle of respect for persons were upheld through the process of informed consent. Participants' written informed consent (See Appendix A for Informed Consent Form) was obtained prior to enrollment and verbally in an ongoing manner throughout the study. Participants were informed of the following: a) the aim of the study; b) any foreseeable risks of participation; c) potential benefits to themselves or others; d) confidentiality protections; e) researcher's contact information for answers to questions regarding the study; and f) conditions of participation, including right to refuse or withdraw at any time without penalty. Participants were periodically reminded that their participation is voluntary and that they have the right to stop participating at any time.

Beneficence was upheld throughout this study. Psychological risks were minimized through the provision of readily accessible social support that is available to the participants through their grief support group. Participants were also provided with a contact list of psychological counseling available in their geographic area. Participants were reminded of their right to withdraw from the study or limit their participation should they become uncomfortable or emotionally distressed at any time. It was anticipated that benefits of participation could outweigh potential harm. It is

true that bereaved parents are a vulnerable population and that psychological risks including sadness, anxiety, and emotional distress may be experienced from participation in this study; however, this type of research does not necessarily pose excessive risk to bereaved parents (Hynson, Aroni, Bauld, & Sawyer, 2006). Rather, in spite of finding it initially painful to talk about their loss, most parents describe interviews as helpful despite their distress (Brabin & Berah, 1995) and most would recommend research participation to others (Scott, Valery, Boyel, & Bain, 2002). Benefits of inviting bereaved parents to participate in research include altruistic intent, being able to talk about their child which helps to keep their memory alive, and having the opportunity to make meaning out of their lived experience (Hynson et al., 2006).

Data were kept confidential and participants' privacy was protected at all times. No identifiers, other than those known only to myself as the researcher, were used. Audio-tapes were stored in a locked cabinet. Written data was saved on a secure personal memory stick and stored in a locked cabinet.

The principle of justice was upheld through the voluntary nature of sample selection. Bereaved mothers and fathers were treated equally and equitably. Sample diversity, representative of mother and father experiences, ensures that all parents will benefit from the knowledge that this study generates.

Participants

Six parents (1 father, 5 mothers) from the Midwest, Mid-Atlantic, and Northeast regions of the U.S., each of whom met the study's inclusion criteria,

volunteered to participate in this study. These English-speaking parents experienced the death of a child, 18 years of age or less, due to cancer at least one year prior to participation and were active participants in a support group.

Children's cancer diagnoses included leukemia, non-Hodgkin's lymphoma, diffuse intrinsic pontine glioma, and medulloblastoma. Children ranged in age from 2-12 years at time of diagnosis and 4-12 years at the time of death.

The amount of time that had passed since the child's death ranged from 1 year, 4 months to 41 years. The minimum time criterion of one year post loss assured that all parents had equal opportunity to reflect back on their bereavement experience for at least one entire calendar year. A maximum time criterion post loss was not imposed in order to promote as full an understanding of the bereavement experience as possible with no impediment of an arbitrary time restriction. The decision to not impose a maximum time limit post loss was made based on recent literature, previously discussed in Chapter II, which suggests that aspects of bereavement may be ongoing in nature. Indeed, this decision to not arbitrarily impose a maximum time limit post loss proved to be very important. It allowed for full exploration of the totality of the lived experience of parental bereavement. Full exploration resulted in the discovery of uniquenesses and commonalities of parental bereavement. Essential themes, shared amongst all parents regardless of the length of time that has passed since their child's death, were discovered.

Setting

Participants were connected to grief support organizations in the United States, including The Children's Brain Tumor Foundation, The Bereaved Parents of the USA, and The Compassionate Friends. Private interviews were conducted with each participant at mutually convenient times. In-person interviews were conducted in parents' choice of setting, including two different neighborhood restaurants, the living room inside one parent's home, and in a parked car near a neighborhood park and school playground. Telephone interviews were conducted in the privacy of my home office.

Gaining Access and Establishing Rapport

I dedicated considerable time and effort to gaining access and establishing rapport with informants and participants. Within one year's time, I cast a wide net in order to gain access to potential participants. I created and maintained an up-to-date, Excel spreadsheet for the purposes of documenting support groups, informants, and potential participants. This record-keeping proved invaluable for organization. I took advantage of every possible opportunity to connect with informants and potential participants alike and followed every lead. I contacted a total of 44 grief support groups, representing both national and local levels. I began with support groups located within close geographic region and expanded outwards when the need became apparent. In my initial telephone and/or e-mail contact to the support group, I introduced myself, provided a brief description of the study, and asked permission to distribute a flyer informing potential participants of the opportunity to participate in

the study (see Appendix B for informational flyer). A few support group informants extended an invitation for me to attend one of their group meetings. Unfortunately, considerable geographic distance prohibited me from doing so. At the time, these particular informants from whom I did receive an invitation did not have attendees who met the study's inclusion criteria; however, had I been able to attend a meeting, attendance might have opened the door to other opportunities. If attendance was possible, perhaps attendees may have known of parents who did meet inclusion criteria but were not affiliated with that particular support group. If attendance was possible, I might have made observations that could have informed future research and might have developed rapport with potential future participants. I also would have been afforded the opportunity to further immerse myself in the field. While support group informants within close geographic distance did not grant permission for me to attend a meeting, they were very willing to post the information flyer. Of the 44 support groups which I contacted, 25 did not reply and 19 replied with great interest. Through 19 support group informants, I gained access to a total of 17 potential participants who volunteered to participate in the study. Of these 17 potential participants, 10 did not meet the study's inclusion criteria. One mother experienced the death of a 16 month old child due to cancer only six months prior. She did not respond to follow-up attempts made to contact her once the minimum of one year's time had passed. Each of the nine remaining interested, yet ineligible, parents experienced the death of a child due to non-oncologic causes such as viral illness,

cardiac anomaly, genetic disorder, and accident. Their children ranged in age of one day to 26 years at the time of their death. Time since their child's death ranged between 2- 20 years. It was very difficult to explain to these parents, all of whom remain active in support groups, that they did not meet the study's parameters. These three fathers and seven mothers from 10 different families experienced the death of a child and wanted so very much to tell their story in hopes of helping others to better understand what parental bereavement is like. I asked each if it would be permissible for me to make note of their contact information for potential future studies to which they most wholeheartedly agreed. This left seven eligible parents who voluntarily consented to participate. One, however, withdrew from the study prior to beginning a first interview. The remaining six eligible parents comprise the study's sample.

Data Collection and Analysis

As discussed above, concurrent data collection and analysis was guided by the interplay of van Manen's (1997) research activities, including: a) turning to the nature of the lived experience of parental bereavement: b) investigating the bereavement experience as parents live it; c) reflecting on essential themes; d) writing and rewriting; e) maintaining a strong, oriented relation: and f) balancing the research context by considering parts and whole.

Audio-taped interviews, lasting between 3-5 hours in total length per parent which aggregated to a cumulative sum of 23 hours, were conducted privately with each parent on two separate occasions. In-person interviews were completed with

three parents. Telephone interviews were completed with three other parents due to considerable geographic distance. During conversational interviews, parents were asked, "Please tell me what it has been like for you since your child died". Each audio-recorded interview was transcribed verbatim as soon as possible after completion. Transcribed interviews were then carefully reviewed while listening to the audio-taped interviews to ensure transcription accuracy. Transcription yielded 621 cumulative pages of typed text.

Mental notations about details observed during interviews were made, but written field notes were kept to a minimum so as to avoid distraction. Mentally noted observations were documented in a written field note log within 24 hours of interview completion.

Four parents shared written expressions of their parental bereavement experience which came in the form of letters and journal entries. This material was unsolicited. Rather, these parents had a strong desire to share this material which they voluntarily offered. Parents were adamant that reading what they had written would help me to better understand their experience. In fact, it did. It mirrored what they verbally shared in their interview.

Analytic memos were written and included reflections from field note log entries, as well as commentary about what occurred in the research process, what was learned, what insights were gained, and leads for further action. Categories of information and initial themes were identified in each parent's analytic memo.

Through the process of writing analytic memos, which amassed to 225 pages of typed text, it became apparent that data saturation was reached when redundancy was found amongst 122 informational categories and 81 initial themes. I synthesized findings from parents' analytic memos into one analytic memo summary document which yielded 149 pages of typed, analytic text. A structure of the meaning of parental bereavement and essential themes emerged from this comprehensive analysis.

Establishing and Maintaining Rigor

Continual attention was given to ensure trustworthiness of this study. Several techniques were utilized. Audio-taped interviews were transcribed within one week of completion. Within two weeks of completion, the audio-taped interview was replayed as the transcribed text was read and edited accordingly to ensure accuracy. A log of field notes with detailed observations was maintained. Documentation was done in a timely manner, with observations noted within 24 hours of each interview.

Participants were enrolled until data saturation was reached as evidenced by redundancy of informational categories and themes. While I would have preferred to have greater participation of fathers, they did not come forward even after quota and snowball sampling attempts. Nevertheless, material gathered from the one father's interview was very similar to that of mothers' descriptions of their lived experience. Analytic memos revealed redundant categories of information and initial themes, indicating data saturation had been reached. Further, participants provided rich, thick descriptions of their lived experiences which yielded vast amounts of interview

material. Data saturation led to a very comprehensive understanding of parental bereavement. Findings are credible.

According to Lincoln and Guba (1989), the criterion of credibility establishes a "match between the constructed realities of respondents (or stakeholders) and those realities as represented by the evaluator and attributed to various stakeholders" (p. 237). Credibility of this study's findings is maximized through the use of multiple strategies in order to establish a match between parents' lived experience of parental bereavement and my interpretation of their experience.

First, I maintained prolonged engagement in the field. Interviews, lasting between three to five hours in total length, were conducted privately with each parent on two separate occasions. Interview dialogues yielded 23 aggregate hours spent in true presence with bereaved parents. When geographical distance permitted, I met parents in their preferred choice of setting. I met Joan in the living room of her home, Kelly in a small restaurant in the center of her hometown, and Peter in a restaurant and near a park near his home. Meeting parents in these intimate settings provided opportunity to establish rapport, build trust, and observe them within their familiar surroundings and context of their daily life. Although geographical distance necessitated telephone interviews with three other parents, I was able to establish rapport and build trust with relative ease. The time I spent engaging in conversational interviews contributed to my ability to do so. Upon parents' recommendations, I also read many written expressions of their lived experience. Five mothers provided

unsolicited written documents to help me better understand what their experience has been like. I engaged in thoughtful, phenomenological reflection of their journal entries and letters which they were most eager to share. I also read and reflected on a popular fiction novel that particularly resonated with Joan and which she strongly encouraged me to read. Further, a key informant highly recommended that I attend a grief workshop and I did so accordingly. Although the study participants did not attend, the workshop was attended by other bereaved parents. Attending this workshop provided me with the opportunity for deep immersion. Second, verbatim quotations from participants were used in order to most accurately capture what parents said and the meaning of that which they said. Third, triangulation was used for the purposes of cross checking data and determining what findings converge across time, space, and persons (Denzin, 1989). Collection of data from bereaved parents at different points in time from their child's death promoted time triangulation. Collection of data from different communities and support organizations helped to test for cross-site consistency promoting space triangulation. Collection of data from different participants (five mothers and one father) helped to validate findings through different perspectives promoting person triangulation. Fourth, I engaged in peer debriefing with my dissertation chair and committee who are expert researchers in qualitative methods, child health, pediatric oncology, and pediatric palliative care. The peer debriefing process provided opportunities to discuss observations, findings, and methodological steps. This process also afforded me the opportunity to debrief

throughout a prolonged field engagement of a particularly intense emotional nature.

Fifth, as a qualitative researcher, I was the data collecting instrument. Thus, my professional qualifications and experience are important elements that give added confidence in the findings. Lastly, I employed a member check process throughout data collection and analysis. Lincoln *et al.* (1989), strong advocates of using member checks to validate findings and interpretations with study participants, state this process “is the single most crucial technique for establishing credibility” (p. 239).

It was of utmost importance to include a member checking process in this particular study. There are several reasons. First, a fundamental aspect of parental bereavement is that no one can truly understand what it is like to experience the death of a child unless they have actually had that lived experience. I am not a bereaved parent; therefore, my written interpretation of the parental bereavement experience needed to be validated by the bereaved parents themselves. If I avoided a return to the field and skipped the formal member check of my written interpretation, the study’s findings would be called into question. Second, during interviews, all parents verbalized great interest in learning what would come of the study. Therefore, if member checking of the written interpretation summary was skipped that potentially could lead to feelings of abandonment. Third, findings indicate that parents search for meaning after a child’s death. All parents indicate that their participation in this study holds special meaning for them. To deny parents the opportunity to participate to the fullest extent possible would deny parents the opportunity to find depth of

meaning. Lastly, parents describe how application of family-centered care principles can minimize added distress after a child's death. If I had not partnered with the parents through the member checking process, parents could have potentially experienced additional distress. For all of these reasons, member checking became of utmost importance to not only increase credibility but also to minimize harm and maximize benefits for study participants.

I engaged in both informal and formal member checks. In real time during each interview, informal member checking was done. I reflected back with the participant to ensure I understood what was being said. I made comments such as, "is that correct", "it sounds like", and "the last time we spoke you mentioned". Parents responded with comments such as, "yeah", "yes", "yes, oh yes!", "that's right", "hmm, hmm", "oh yeah!", "right". Sometimes, parents would quietly nod their head to indicate that I accurately understood the meaning of what they had said. Parents often repeated to give further emphasis and expanded their thoughts which added to rich, thick descriptions of their experience.

Formal member checking was also done. My interpretive summary describing parents' collective experiences was shared with each participant. Each parent was offered the choice as to whether they wished to read the written summary and give feedback. All parents eagerly expressed great desire and appreciation for this opportunity. I encouraged each parent to take as much time as they needed and to call me any time they wished to discuss. I also informed parents that they could chose to

stop reading or participating at any point. Parents' feedback as to whether the written summary resonated with them was solicited. Specifically, parents were asked "Does the summary resonate with you?" and "Do you see enough of your own experience in the summary that you think could help other parents?" Overall, feedback was very positive. For example, Peter responded, "Thank you for working on this. I believe it will be helpful for other families" (Peter, personal communication, October 14, 2013).

Sara said:

I really appreciated the summary. You did a great job. I really do see a lot of myself in it and it's helpful to see I am not the only one feeling this way. Seeing how other parents feel helps me to feel less isolated. It was very thorough, not just the content but also I really liked how you laid it all out, the way you worked with this and the words you used. (Sara, personal communication, October 22, 2013)

Reflecting the degree to which my interpretive summary resonated with parents, I am honored to have received an invitation from the American Childhood Cancer Organization to author a chapter on the lived experience of parental bereavement, including grief, in the first palliative care reference book that is being written for parents of children with cancer. This invitation came as a result of one participant's collaboration with the American Childhood Cancer Organization on the project. Parents' feedback validates my written interpretation of their lived experience and further supports credibility of findings.

Chapter IV

PARENTS AND THEIR CHILDREN

Five mothers and one father from six different families volunteered to share their story of what it has been like for them since their child died. Each parent began by sharing special qualities about their child and a detailed account of the circumstances surrounding their child's death. Parents shared their stories in such a way that I came to feel as though I personally knew them, as well as their children. Extremely powerful, heart wrenching stories follow.

Joan, Joshua's Mother

Joan is Joshua's mother. Joshua was a sensitive, loving, affectionate, and kind boy who was wise beyond his years (pg 22, lines 11-14, 16-23; pg 23, lines 1-5, 8-12). Joshua was nine years old at the time of his non-Hodgkin's lymphoma diagnosis and 11 years old at the time of his death. Fifteen years have passed since Joshua's death.

Joan tells of Joshua's illness, including his diagnosis with a favorable prognosis of 85% chance of remission (pg 1, lines 13-14, 17-18, 20-21; pg 2, lines 1-4); his relapse after one year of chemotherapy treatment (pg 2, lines 8-16); and his eventual death 100 days after undergoing a bone marrow transplant (pg 3, lines 4, 6-9) and treatment with experimental medications (pg 15, lines 14-20). Joan had to be brave during Joshua's illness and put on her *happy face* in order to remain focused on his needs rather than her own feelings (pg 17, line 20-21; pg 44, lines 21-22). Joan

explains, “I couldn’t feel my feelings at the time, ‘cause I felt at times that I was just... going to be gone...from the experience” (pg 44, lines 16-17, 19).

Joan was not able to tell Joshua that he was dying (pg 17, line 22-23; pg 18 lines 1-20; pg 81, lines 13-23) because “it was very difficult...very, very difficult” (pg 81, line 22). Joan says, “how do I tell an 11 year old that he is dying? There is no way that I can tell him that” (pg 81, lines 15-16). She questions if this is something that other parents are able to do (pg 81, line 23). Near the end of life, Joshua was comatose and Joan felt a sense of relief because this heavy, awful burden of having to tell her son that he was dying was removed for her (pg 82, lines 2-8). Joan still thinks about this 15 years later, saying “I don’t know if he ever knew he was dying” (pg 82, line 8) and “I still think to this day I couldn’t tell him” (pg 81, lines 16-17).

Joan is haunted by excruciating vivid details that surrounded Joshua’s illness and death. Joan describes “horrible scenes...of being in a war zone... having this child dying...it was just like being on the front lines” (pg 16, lines 1-9, 15-18, 20-23; pg 17, lines 1-13, 15-19). Joan shares the following example of what it was like for her to be on the front lines of the war zone with her dying child:

I remember...my son was intubated...they had this pull-out toilet from in the [ICU] room...he was sitting on this toilet and all of a sudden he said, ‘I can’t breathe’ and there was a nurse there with him, helping him, because he had, he was just wired everywhere. So I guess she just pulled the call button and she put him back on the bed and they started doing CPR on him and everybody came in the room...they didn’t ask me to leave...I was just standing at the front of the bed watching them... witnessing this whole thing going on. (pg 16, lines 15-18, 20-23; pg 17, lines 1-3)

After Joshua died, Joan began a “totally different” life (pg 32, line 9-10; pg 33, line 5-7). Joan says, “I’ll never be the same. I’ll never be the woman that I was prior to Joshua’s death or illness. That woman is gone” (pg 46, lines 14-16).

Sara, Adam’s Mother

Sara is Adam’s mother. Adam had a “sweet spirit” (pg 6, line 12-15) and a sense of humor that brought “lighthearted moments” to his family (pg 4, line 13-23; pg 5, lines 1-4, 22-23; pg 6 line 1-5; pg 7, line 6-8). At the age of six, Adam was diagnosed with diffuse intrinsic pontine glioma (DIPG), an inoperable tumor in the pons considered to be terminal at diagnosis.

Sara vividly remembers receiving the news of Adam’s DIPG diagnosis, which came during the same week that she herself was diagnosed with breast cancer (pg 5, lines 11-18, 22-23; pg 6, lines 1-5). There is a pervasive sense of powerlessness that comes with a child’s DIPG diagnosis. Sara states, “to be told from day one your child is going to die unless there is some kind of miracle that occurs...there is nothing that we can do about it” (pg 35, lines 16-18).

Sara tells of the many honest conversations she had with Adam about his fears of dying (pg 46, lines 17-20, 22-23; pg 47, lines 2-9, 11-12, 14) and the ways in which Adam exhibited both maturity during illness (pg 6, line 7-10; pg 7, line 14-19) and grace in dying after he made the decision to stop his treatment (pg 6, lines 14-16, 21-23; pg 7 line 1-5). While every child is developmentally and emotionally unique, it is

reported that seriously ill children as young as six years of age are capable of participating in discussions and decision-making about whether or not to continue their treatment (Hilden, Watterson, & Chrastek, 2000; Hinds, Menard, & Jacobs, 2012; Nitschke *et al.*, 1982; Nitschke, Meyer, Husztic, 2001). This, in fact, is true in Adam's case. Sara explains:

By the end, he knew that he was dying...he was the one that made the decision to stop treatment...at the very end, he was the one who decided to stop treatment and he knew what that meant and he was fine with that and he died exactly two weeks later...when he made the decision that he was done... that nothing was really gonna help, then...he died. (pg 6, lines 11-12, 15-16, 23; pg 7, lines 1-2, 4-5)

Further evidence that Adam not only knew he was dying but also participated in decision-making to cease treatment can be found in Sara's written journal which she offered to share. In her journal, Sara includes a quote from Adam five months prior to his death in which he says, "when I go to Heaven, I'll have lots of friends there" (Sara, personal communication, pg 74, line 9, July 6, 2009). Two days prior to Adam's death, Sara writes the following in her journal:

The tumor had progressed. In fact the entire brainstem and much of the cerebellum are tumor. There is also involvement of the thalamus, the hypothalamus and the temporal lobe. It was surprising to see the scans and know that Adam was awake, interactive, and free of pain. In spite of the scans, Adam qualified for [a research] study, and we signed the papers in preparation to begin the protocol. Over the next couple days Adam made it clear both to us and to [his doctor] that he no longer wanted to participate in the study. Knowing that it was amazing that he was awake, eating small amounts of a wide variety of foods, and enjoying teasing his doctor about the Mavericks, we felt that as parents we could ask no more of him. (Sara, personal communication, December 2, 2009, pg 47, lines 36-39; pg 48, lines 1-6)

At the age of eight, Adam died two years, one week, and one day after diagnosis. Two and one-half years have passed since Adam's death. About Adam, Sara states, "he will always be the son that the last time I saw him, he was eight years old" (pg 93, lines 5-6). Of herself, Sara states, "I will always be a bereaved mother. I will always be a mother who lost a child" (pg 107, line 18-19).

Kelly, Sam's Mother

Kelly is Sam's mother. Kelly lovingly recalls Sam's caring nature (pg 54, lines 2-3), his athletic talents and love of outdoor sports (pg 2, lines 2-3; pg 5, line 13; pg 6, line 21; pg 33, lines 1-2; pg 57, lines 19-21), and sense of humor (pg 67, lines 13-14, 21; pg 67, lines 13-14). Sam's presenting symptoms were so subtle, yet progressive, that it came as such a horrific shock for Kelly when he was diagnosed with medulloblastoma just six days after initial symptom onset (pg 2, lines 1-14, 18-23; pg 3, lines 1-3, 5-9, 11, 13, 15, 17, 20-23; pg 4, lines 2-3, 5-8, 10-16; 18, 20-23; pg 5, lines 2-10, 12-22; pg 6, lines 1-4; pg 18, lines 5-7). Despite the pediatric oncologists and neurosurgeons' optimistic reassurances of a good prognosis, subsequent biopsy results indicated only a 5% chance of survival leaving Kelly and her husband, Michael, in a state of disbelief (pg 6, lines 6-11).

Kelly recalls Sam's treatment, including surgical resection (pg 6, lines 2-4), chemotherapy (pg 6, lines 12-14; pg 7, lines 20-23; pg 13, lines 18-21; pg 14, lines 1-2, 4-6, 8-10), and radiation (pg 6, lines 14-18, 20-23; pg 7 lines 2-11, 15-20). During Sam's hospitalizations, she and Michael made the best of the situation for Sam by

keeping a sense of humor, telling silly jokes, and laughing (pg 67, lines 16-18, 20-21; pg 68, lines 1-5, 7-8). As a result of using humor to cope, they were perceived by hospital staff to be “a very popular family” (pg 68, lines 10-11). Yet, at the same time, they were strong advocates for Sam’s safety during hospitalizations and were not afraid to speak up in order to avert errors in medication administration (pg 68, lines 12-13, 15, 17-18), diagnostic imaging procedures (pg 68, lines 19-23), and communication (pg 69, lines 1-5, 9-10).

When Sam relapsed twice within eight months, Kelly recalls not opting for a second opinion because “it was a losing battle...Sam’s cancer was so unique” (pg 15, lines 18-19) and it was “obviously fast growing” (pg 15, line 22). In spite of physician recommendations to stop treatment (pg 7, lines 10-11), Kelly and Michael wanted to continue fighting for more time with him and pushed for doing a stem cell transplant (pg 7, lines 22-23; pg 8, lines 1-2, 4-13, 15-17; 19-23; pg 9, lines 1-3). Sam’s hospitalization for stem cell transplant was scheduled for the day following his return trip home from his Make-a-Wish beach vacation (pg 9, lines 2-4). However, Sam experienced a seizure during the flight home and died five days after transport to his treating hospital (pg 9, lines 4-17).

In spite of knowing Sam wasn’t going to survive, Kelly wasn’t prepared for the actual moment of his death (pg 47, lines 13-19) which came one year following diagnosis. One and one-half years have passed since Sam’s death. Kelly shares a personal letter she wrote to Sam:

Will you walk beside me now as a friend, comrade, loving son? I cannot come to you at this time, I can only trust that we will be reunited in God's love and compassion. But my life must go on; it is time for me to begin to live my life for myself and others. As I think of letting you go. I must now ask that you also let go of me. Your new life must seem as strange to you as my new life seems to me; perhaps the memory of me is as comforting to you as your memory is to me. Let us, then, agree to explore these new existences, these new spheres of reality, knowing that we carry, the other with us, not with chains, but with loving, open hands. (Kelly, personal communication, May 24, 2012)

Doris, Cindy's Mother

Doris is Cindy's mother. Doris and her husband, Roger, adopted Cindy from Korea when she was six months of age. After an eight week hospitalization for apnea of prematurity, Cindy grew and developed steadily. Cindy was healthy at the time of her adoption and thrived throughout her early childhood years. Cindy was a very strong-minded (pg 3, lines 18-22; pg 4, lines 1-12, 14, 22-23; pg 5, lines 1-5; pg 6, lines 11-12), self-assured (pg 3, line 19-20; pg 7, lines 8-9), independent (pg 7, lines 14-22), social (pg 3, lines 22-23), empathetic (pg 4, line 20), kind (pg 4, line 21), and happy (pg 3, line 18) child. Cindy thoroughly enjoyed music (pg 96, line 15). She played two instruments (pg 4, lines 17-18) and performed vocally (pg 4, lines 20-21; pg 95, line 16). She enjoyed theater (pg 29, lines 5-6; pg 96, line 15) and dance (pg 95, line 15). She was physically fit (pg 30, lines 7-9) and competed in both swimming (pg 5, lines 7-12; pg 7, lines 2-5) and track (pg 4, lines 12-13, 15-18). Doris states:

[Cindy] was awesome...I know from the bottom of my heart that when we...chose to adopt...she was specifically chosen for us...I wouldn't change any of that. I would give my life to have her back, but I wouldn't not not go

through with having had her as my child because of what I know now...she was the world to me (pg 5, lines 21-22; pg 6, lines 2-5, 10).

As the biological mother of Kevin and adopted mother of Cindy, Doris states:

I feel like I am one of the best spokespeople for saying I loved my children absolutely no differently. One I gave birth to. The other was born out of my heart...the love, the feeling that I was their parent is no different. (pg 87, lines 22-23; pg 88, lines 1-2)

At the age of 12, Cindy was diagnosed with diffuse intrinsic pontine glioma (DIPG). Doris vividly and precisely recounts every detail of Cindy's illness from her first symptom to her death, which came 224 days following her DIPG diagnosis (pg 20, lines 14-15). Doris remembers this period of time as being "surreal" (pg 6, line 20; pg 14, lines 17-18; pg 19, line 21) because everything before was "all so good and all so normal" (pg 7, lines 11-12).

Cindy's initial symptoms were so subtle that only now is Doris able to attribute them to her brain tumor diagnosis (pg 6, lines 21-23; pg 7, lines 1-2; pg 19, lines 11-19). It all started on July 7th when Doris first noticed Cindy was drooling (pg 8, lines 2-3, 8-9). Doris brought Cindy to her family nurse practitioner who diagnosed her with Bell's palsy based on presenting symptoms, including drooling and facial numbness (pg 8, lines 2-3, 8-11, 15-18). Doris insisted that Cindy have an MRI because she was uncertain about the accuracy of this diagnosis given all that she had read about Bell's palsy being uncommon in children (pg 9, lines 7-12, 14-19; pg 10, lines 11-15, 17-19). On Monday, July 27th, Cindy was seen by a neurologist who concurred with the Bell's palsy diagnosis but agreed to an MRI to alleviate Doris's

concern (pg 10, lines 22-23; pg 11, lines 1-5). On Tuesday, July 28th, Cindy had the MRI at 10am (pg 11, lines 12-17, 22-23). Just before 12pm, with the utmost urgency that to Doris felt like “don’t pass go, don’t collect \$200, just get in your car and head back to the doctor’s office” (pg 12, lines 9-10), the MRI technician instructed Doris to return immediately to the neurologist’s office (pg 12, lines 1-15). By 2pm, after reviewing Cindy’s MRI results, the neurologist asked Doris and Roger if they were willing to travel to the Children’s Hospital for treatment (pg 12, lines 22-23; pg 13, lines 1-2). Doris says, “I would have gone to the moon, for crying out loud! I went to Korea to get her...so traveling is not a big deal” (pg 13, lines 4-5). Doris recalls “not comprehending anything, but planning” (pg 13, lines 9-10) and explains, “my head was making plans even though I still kept trying to make myself believe either it was just some oddity that...he just wasn’t familiar with” (pg 13, lines 10-12).

On Wednesday, July 29th, Doris and Roger traveled with Cindy to Children’s Hospital where they received news of Cindy’s DIPG diagnosis (pg 14, line 13). Doris states:

That day is just a blur...it just feels so not real. It’s like that time when you go from being you to being a poster child for the St. Jude’s calendar...you felt so...bad for those parents before...but you could never place yourself there.
(pg 14, lines 14, 17-21)

Doris recalls very specific images of that day. She remembers the slow elevator ride up to the pediatric oncology clinic (pg 16, lines 6-7). She remembers feeling shocked upon seeing all the sick children in the waiting room (pg 16, lines 8-16). She remembers sitting in a very small consultation room, illuminated by sunlight shining

through one window through which she could see a church in the background (pg 15, lines 5-7; pg 17, line 23; pg 18, line 1). She still sees the sunbeam as it bounced off the top of the physician's balding head creating a halo-like effect (pg 18, lines 7-8, 16). She remembers how her eyes welled up with tears before the physician said these words: "Cindy has a... diffuse intrinsic pontine glioma...this is the worst diagnosis I can give to a parent" (pg 18, lines 8-12). Cindy's diagnosis changed everything in Doris's life (pg 25, lines 11-19, 23; pg 26, lines 1-3). Doris explains:

Everything you know is different...every piece of your life is different. You can't go to the grocery store anymore...you're not comfortable in church...people are afraid of you...people say really goofy things...people look at you different...you look at yourself different...every single thing revolves around [Cindy's cancer]... all I remember thinking was we might not have her here this time next year. We might not get to do this again. (pg 25, 11-16, 23; pg 26, lines 1-3)

Cindy never talked about dying with Doris, but rather held on tightly to the hope of recovery (pg 27, lines 15-16; pg 47, lines 15-16). Cindy was an active decision-maker in her care, whether it was controlling her daily dosage of Decadron® based on how she was feeling (pg 32, lines 13-21; pg 35, lines 15-16, 18, 21-23; pg 46, lines 13-16) or indicating her wish to stop medical care provided by multiple residents by wiggling her finger and saying "no more white coat" (pg 41, lines 4-13, 15, 17-18, 20-22; pg 42, lines 1-2, 4-5). Doris says, "I felt like in the end I couldn't give her enough information...because I know she was afraid at the end and I didn't want her to be afraid" (pg 33, lines 14-15, 17-18).

Doris and Roger communicated their wish to never have Cindy suffer and made treatment decisions based on Cindy's quality of life (pg 22, lines 8-9, 11, 14; pg 38, lines 4-10; pg 49, lines 1-3; pg 82, lines 5-6, 8-10, 13-16, 22). For example, since Cindy didn't want to be bald and didn't want a port-a-cath (pg 22, lines 1-2, 4), Doris and Roger chose phase I clinical trials that incorporated oral Decadron® and radiation therapy (pg 22, lines 6-9, 20-23). To support Cindy when it came time for her hair to be cut prior to radiation therapy on July 31, Doris also cut her own hair (pg 27, lines 20-23). On days when Cindy was feeling well enough, Doris and Roger took Cindy to school (pg 29, lines 10-15), to the zoo (pg 28, line 13), to various sightseeing attractions (pg 28, lines 5-12), and to the theater (pg 29, lines 4-8). Doris decorated cupcakes with Cindy (pg 34, line 2), took her to visit friends (pg 34, line 2), and gave her pajama parties (pg 34, lines 5-9). Doris spent a significant amount of money on pretty clothes for Cindy (pg 31, lines 9-11). Doris did everything she possibly could to make Cindy feel like a 12 year old little girl (pg 34, lines 8-9). When Cindy began her second clinical trial, Doris chose not to bring Cindy to clinic for the optional blood tests because as she explains:

I was being selfish...and...it was more difficult for Cindy to go back and get stuck five or six times and have to sit in the day hospital all day and...by that point...I knew that I was losing her and I felt like I just didn't want...to share.
(pg 28, lines 19-22)

By the time radiation therapy finished on September 19th, Cindy's quality of life was significantly affected by treatment side effects (pg 30, lines 4-9, 11-19, 21-23; pg 31, lines 7-8; pg 33, lines 6-7; pg 34, line 4). On December 1st, Cindy made her

Make-a-Wish trip to Hollywood (pg 31, line 1; pg 32, lines 2-8, 10-11; pg 33, lines 4-5). On January 28th, Cindy weaned off steroid medication (pg 32, lines 13-22).

On February 2nd, the first tumor bleed occurred (pg 35, lines 14-16, 18-19, 21-23; pg 36, lines 1-6, 8-14, 16-23), followed by a second tumor bleed between February 18-20th (pg 47, lines 22-23; pg 48, lines 1-4). After the first bleed, because time was of the essence, Cindy's pediatric oncologist instructed Doris to bring her to the local emergency room where he managed her care by communicating with the staff via cell phone until she was stable enough for transport to the Children's Hospital (pg 37, lines 6-10, 12-13, 15-22). Doris remembers the fear she felt this day, saying:

That was probably the scariest day of all. That was definitely the scariest day because even though [Cindy's pediatric oncologist] was on the phone,...I was terrified that if she had coded they wouldn't follow my DNR...I just didn't trust that they wouldn't do the DNR. (pg 37, lines 22-23; pg 38, lines 1-4)

Cindy was eventually admitted to Children's Hospital's inpatient pediatric oncology unit for end-of-life care (pg 20, lines 18-22; pg 34, lines 12-18, 20-22; pg 35, lines 1-2, 4-5; pg 38, lines 14-15, 17-23; pg 42, line 7; pg 43, lines 8-12, 14, 16-17; pg 45, lines 19-20; pg 48, lines 6-10, 12-13, 15-16). Doris and Roger considered the alternatives to hospital care; however, given the fact that an inpatient pediatric hospice bed was not available and the family's concerns of poor pain management at home, they made the decision to stay in the hospital with the support of Cindy's oncologist (pg 54, lines 14-21, 22-23; pg 55, lines 2, 4-6). On March 7th and 8th, Doris and Roger attended a team meeting with the pediatric palliative care and neuro-oncology services to discuss Cindy's clinical condition and pain management plan (pg 51, lines 16-19,

21-22; pg 52, lines 1-2, 4-11, 13-23; pg 53, lines 1-5). While the physicians felt Cindy was nonresponsive to painful stimuli based on physical examination (pg 51, lines 18-19, 21-22; pg 52, lines 1-2; 4-6,11), Doris and Roger felt she had communicated with them (pg 52, lines 2, 6-11) and had “advancing pain” (pg 52, lines 16-17). Doris and Roger wanted to increase her pain medication dosage; however, the physicians were reluctant to due to fear of respiratory depression (pg 52, lines 17-19; pg 53, line 4).

Doris recalls:

[This] was the only time [my husband] really lost it...he lost it because...she had spoken to us minimally but it was meaningful. [She] had, and we still believe...this might be the time we were the ‘cranky parents’... but we really believe we had had communication with her that day so we disagreed with different versions based on his physical exam test that she really wasn’t there. (pg 52, lines 6-11)

Doris goes on to say, “I remember the one doctor looking me squarely in the eye and said...if I upped her pain meds, that...she would die” (pg 52, line 21). Doris calls this her “Kevorkian experience” (pg 52, line 22). Doris explains:

[It was] like I was helping her to leave but legally...I knew we were at a level that if we increase her narcotics and decrease her respirations that...we could in fact hasten her departure. That wasn’t what I was trying to do. It wasn’t about that. (pg 52, lines 22-23; pg 53, lines 1-3)

Doris didn’t want Cindy to suffer (pg 38, line 5). On March 10th, at 2:30am, Cindy died with Doris by her side (pg 51, line 16; pg 53, lines 6-14).

Time passed so fast from the day of Cindy’s diagnosis to the day of her death (pg 14, line 4; pg 20, lines 4-6, 10, 13; pg 22, line 19; pg 24, lines 19-20; pg 33, lines 12-13, 20-21; pg 34, lines 9, 11-12; pg 51, line 3). Doris explains it felt “like a

tornado...a whirl-wind” (pg 33, lines 20-21) because “everything goes so fast...you don’t have time to...breathe” (pg 22, line 19). While she feels there was not enough time, Doris says “no [amount of] time gets better knowing your child’s going to die...in 224 days she’s gone...that’s just [not enough time]...not that you’re ever ready...but how do you get ready in 224 days?” (pg 20, lines 5-6, 10, 13). Doris adds, “it makes me sad that it happened all so fast and I always think that until I die, I will always wish that we had more time, but I also didn’t want her to hang out and suffer for our benefit” (pg 82, lines 22-23; pg 83, lines 1-2).

Cindy was 12 years old when she died. Two and one-half years have passed since her death. In contrast to the rapid passage of time during Cindy’s illness, time since Cindy’s death has come to a halt. Doris says:

I can’t believe that it has been two years since she died and yet it feels like it still was yesterday...that’s the part that just doesn’t make sense to me. How two years goes by and that’s a long time and I don’t feel that different! I still wake up and expect to hear her voice some days...it’s been two years but it doesn’t feel like it’s been two years. (pg 71, lines 15-17, 19-23; pg 72, lines 1-2)

Peter, Robert’s Father

Peter is Robert’s father. Robert was academically gifted (pg 1, lines 10-13; pg 6, lines 7-12). He especially excelled in math (pg 1, lines 1-3, 6; pg 6, lines 13-15). In fact, math was a game that he and Peter enjoyed playing together (pg 2, lines 15-18, 20-22; pg 3, lines 1-2). Robert was always eager to please (pg 12, lines 18-19; pg 31, lines 17-22). For example, when Peter asked Robert to clean his room, Robert

responded, “I know it’s a pig sty Dad and I’ll get right on it” (pg 12, lines 18-19).

Peter says:

I know everyone else’s kid was fantastic and wonderful too and sometimes I think that...maybe I go back to thinking about it in a romantic sense...now that he’s passed, he’s perfect! No, he wasn’t perfect but he was pretty darn good. (pg 1, lines 20-13)

Robert was 11 when he was diagnosed with diffuse intrinsic pontine glioma.

Peter recalls the suddenness of Robert’s subtle symptoms, including foot drop (pg 7, lines 6-7), falls (pg 7, lines 7-8, 10-11), eye deviation (pg 7, lines 19-22), slurred speech (pg 7, line 23; pg 8, line 1), and ataxia (pg 8, lines 8-10). Peter says, “I didn’t know what was going on...now of course everything’s crystal clear, but then I didn’t think anything” (pg 8, lines 1-3, 5-7). Peter and his wife, Trisha, took Robert to the pediatrician (pg 7, line 8), who immediately directed them to the local emergency department (pg 8, line 7) for a diagnostic workup (pg 8, line 9). Within one hour, Peter and Trisha were told Robert had a brain tumor (pg 8, lines 10-11). Peter says:

We’re looking at the MRI and all it looks like is a white blob. I’ve seen an x-ray here and there...by no means am I someone who can read an MRI, but I was looking for a dot...and it was just white. I didn’t know it was only just supposed to be not that big. (pg 8, lines 12-15)

It wasn’t until two days later that they realized the seriousness of Robert’s diagnosis (pg 8, lines 16-18), after having done some investigation on their own via the computer. Robert was soon transferred to a children’s hospital with a designated pediatric oncology specialty treatment center (pg 8, line 18). Robert received radiation therapy (pg 10, lines 1-2) and Decadron® (pg 26, lines 14-23), from which

he experienced horrible side effects including polyphagia (pg 26, lines 14-20), irritability (pg 27, line 21; pg 31, lines 16-17, 22-23; pg 32, lines 1-13, 15-16), and an accumulation of adipose tissue that completely altered his physical appearance (pg 26, lines 20-23; pg 27, line 1).

Peter talked with Robert about his illness at a level that he could understand (pg 1, lines 24-25; pg 2, lines 1-12; pg 24, line 23; pg 25, lines 1-3). For example, Peter says, "I told him he had a tumor" (pg 1, line 25). Peter explains how he reassured Robert that getting cancer was not his fault:

Right from the beginning...I sat him down and said this isn't something that you did. It's not because of something you did. You had no involvement in this. You have no common denominators, not because you lived here, or eat this, or do that. (pg 24, line 23; pg 25, lines 1-3)

When Robert asked how long he needed to have chemotherapy treatment, Peter answered, "you have cancer and we're trying to fight it and we're gonna have to take guidelines from the doctor" (pg 2, lines 4-6).

Robert adhered to all the treatment he received (pg 33, lines 13-14). Robert recognized the effects that the tumor and treatments were having on his body (pg 2, lines 9-12). For example, after completing radiation therapy, Peter recalls Robert saying: "I used to be one of the sharpest tools in the shed. Now, not so much anymore" (pg 2, lines 12-13). Robert understood he was dying (pg 2, lines 8-9; pg 33, lines 11-13). Peter explains:

Robert knew. He didn't say, but he knew. The first day we were at the [hospital]...he says, 'How's your mom?' And I say, 'Robert, you know my mother's dead right?' She died before he was born. 'Yeah, but how is she?'...

‘Well, she’s in Heaven and I believe she has no more pain and she’s happy and she’s comfortable and...she’s enjoying all the good things that Heaven has and all her pain and earthly...burdens are gone. But Robert, you know that she’s dead?’ ‘Yeah, I know, I just wondered how she is’. And then later on, Child Life told us that children try to protect their parents as much as the parents try to protect the child. (pg 16, lines 12-20)

Robert was intubated for respiratory distress (pg 28, lines 17-19) and eventually extubated (pg 29, line 12; pg 30, lines 7-8, 12-16). Peter recalls:

They extubated him and it wasn’t good...they shut all the alarms off and everything else...I don’t have a medical degree. I didn’t even take psychology in college. He was done. He was gone at that point. And then he just opened his eyes and took a deep breath and he held on for a couple more days. (pg 30, lines 7-8, 12-16)

When Peter thought Robert was imminently dying after extubation, he began speaking words of reassurance and maintained presence. Peter says:

I had read somewhere that the biggest fear for kids is being in pain and are they alone and being forgotten. So I started [talking to him] and luckily my daughter and my wife chimed in because they didn’t know what I was doing. I didn’t know what I was doing. (pg 30, lines 8-12)

Under home hospice care (pg 9, lines 14-16, 18-22; pg 10, line 1; pg 30, lines 18-23; pg 31, lines 1-3), Robert died a few days following extubation, just five months after diagnosis at the age of 11. One year and four months have passed since Robert’s death. Peter says, “there is no making it better. I wish. I could sit here and second guess everything I’ve done. It’s been over a year, what are we going to do?” (pg 34, lines 19-21).

Emma, Dorothy’s Mother

Emma is Dorothy's mother. Dorothy was "a very, very strong little girl, very wonderful little girl" who loved to dye Easter eggs (pg 11, lines 11, 19-20). Dorothy was a healthy child (pg 3, lines 3-6; pg 53, lines 6-7), until she was diagnosed with leukemia at the age of two (pg 2, lines 21-22; pg 3, lines 10-11). Dorothy's presenting symptoms included a two week history of fever (pg 53, lines 8-11), followed by vomiting (pg 53, line 12). Emma says, "it was a terrible shock" (pg 3, line 17).

Emma knew a little about leukemia because her cousin had also died of leukemia in childhood (pg 3, lines 19-22; pg 53, lines 15-21). Although Emma was 10 years old at the time, she says, "I remember my family members saying that my Aunt Jenny was losing her mind...from the loss" (pg 3, lines 20-22). Upon receiving the news of Dorothy's diagnosis, Emma recalls, "the doctor told my husband not to let me read anything on it and, of course, I went right to the library and read everything I could get my hands on" (pg 4, lines 4-5).

Following a 30 day hospitalization at diagnosis (pg 4, lines 7-8; pg 53, line 14), Dorothy went into remission for one year (pg 4, line 8; pg 53, line 15). Emma says, "I just never believed we were going to lose her no matter what they said" (pg 4, lines 10-11). The doctor informed Emma and her now ex-husband, Arthur, about experimental treatment being offered at another hospital, but since they did not want Dorothy to suffer they did not pursue further treatment (pg 9, line 23; pg 10, lines 1-5, 7-8). Emma was surprised how alert and communicative Dorothy was up until the time of her death, (pg 9, lines 18-19; pg 11, lines 7-17), unlike her own parents who

were unresponsive (pg 9, lines 16-19; pg 11, lines 16-17). Emma recalls the conversation between Dorothy and her doctor on the day that she died:

Her doctor came in. He saw her an hour before and I guess he realized that was going to be his last time, because when he walked in the room...I'll never forget it, she said 'no more needles doc' and he said, 'no baby, no more needles'. (pg 10, lines 14-18)

Three days before Thanksgiving, Dorothy died at the age of four (pg 4, lines 14, 16; pg 9, line 9). Emma's father, her "rock" whom she misses dearly (pg 11, lines 21-22), drove Emma home from the hospital the day Dorothy died just as he had driven her to the hospital the day she gave birth to Dorothy (pg 11, lines 22-23; pg 12, lines 1-3). A few years ago, Emma started to wonder how her clothes that had been left at the hospital on that day were returned to her (pg 12, lines 5-12). She asked Arthur last year, but he couldn't remember either (pg 12, lines 7-9). About this specific detail, she says, "I don't know why that suddenly...came to my attention, but...I just don't remember...maybe my brother went and got it, but I don't know...I don't know" (pg 12, lines 9-12). Emma reminisces back to November 21, 1971 searching for this missing detail as she reconstructs the events of that day as if remembering this very specific detail would help put her at ease. Emma vividly remembers her father and her husband planning Dorothy's funeral, recalling:

That night the funeral director came to my parent's house. I remember we sat around the table and he brought...a loose-leaf book of pictures...we didn't have to go pick out...the little white casket....my husband did all the arrangements. I sat there like...a lump...the only thing I did say...[was] I couldn't let her go on Wednesday and so we set it for Friday [because of Thanksgiving holiday]...that happened to be our anniversary but I didn't care. (pg 12, lines 12-15, 18-19; pg 13, lines 6-8)

And so it was that Dorothy was buried four days after her death on Emma and Arthur's wedding anniversary (pg 4, line 22; pg 5, lines 1-2; pg 13, line 8). Dorothy's two maternal uncles, her godfather, and a family friend served as the four pallbearers (pg 13, lines 10-12). Emma remembers that day:

The day that Dorothy was buried, the day after Thanksgiving, it was so cold...she's on a hill...and that wind, oh my goodness! Well, I didn't care about the cold, but...my friend told me not too long ago, 'Emma, I've never been that cold in my life'....whatever you told me to do, I'd do it. Well [this] one time I said I wasn't leaving the cemetery and leaving her there because it was too cold. And I remember my priest took one of my arms and he said to my husband, 'take her other arm', and they dragged me and put me in the limo...it was...really, really bad. (pg 28, lines 21-23; pg 29, lines 1-9)

After the funeral, Emma lived with her parents for two weeks before going back to live with Arthur (pg 40, lines 18-19, 21-22). She says, "it was difficult [returning home], but I was trying to manage" (pg 40, lines 21-22).

Forty one years have passed since Dorothy's death. Emma wants "people to know that she did exist and she was and is still my daughter" (pg 14, lines 11-13). Although Emma says, "I am and I always will be" (pg 22, line 8) Dorothy's mother, she is forever changed. Emma says, "You can never go back and be that same person again. You never, ever can go back" (pg 46, lines 2-4).

Here begins the story about what it is has been like for these parents since their child's death. It is through each parent's story that the meaning of the lived experience of parental bereavement emerges. To experience parental bereavement means to enter a new state of being in which the parent endures profound suffering,

maintains the parenting relationship in the presence of the child's absence through acts of remembrance and honor, experiences a renaissance of self, and journeys towards healing sustained by support and hope.

Chapter V

NEW STATE OF BEING

Parental bereavement is a new state of being into which parents enter immediately after the death of a child. This new state of being exists throughout the parent's lifetime and has no end point. In this new state of being, parents experience profound suffering, maintain the parenting relationship in the presence of the child's absence through acts of remembrance and honor, experience a renaissance of self, and journey towards healing sustained by support and hope.

Life Is Completely Different

After the death of a child due to cancer, parents are thrust into a new state of being where life is completely different than before. When parents describe what it has been like for them since their child's death, they use phrases such as, 'totally different', 'a new life', 'a new point', 'a new sphere of reality', and 'a new state of being'. For example, Joan describes her life in terms of before and after Joshua's death. Joan says:

There's a point in my life where there is line zero...before Joshua died [is] on top [of the line] and below [the line] Joshua died is now, here on in...that is my new point...day one... There's nothing in my life that I don't think has changed. (pg 3, line 10-12; pg 33, lines 6-7)

Kelly describes life after Sam's death as a "new sphere of reality" (Kelly, personal communication, May 24, 2012, line 24) and the beginning of "a new life" (pg 112, lines 12, 14) without Sam's physical presence. Emma also describes the beginning a new life after Dorothy died (pg 16, lines 1-2; pg 30, line 3, 16-18, 21-23; pg 31, line 1; pg 44, lines 7-9, 11; pg 46, lines 2-7; pg 52, line 23). Even though 41 years have passed since Dorothy's death, Emma says "life never, ever goes back to the same point as it was" (pg 16, lines 1-2). Consequently, what was once considered normal ceases to exist.

After a child's death, a parent's life will never be normal. Emma explains:

Life...doesn't go on! It doesn't go on for a long time, and even when it does go on, ...it's not...normal...it will never be...normal...what was normal before her death and what's normal now are two completely different things... it's a new kind of normal...it will never be normal. (pg 30, lines 16-18, 20-21; pg 44, 11)

Before Dorothy's death, normal for Emma meant "having my two children and thinking that ... I had a perfect family" (pg 53, lines 4-6). Even after 41 years, Emma never experienced a return to normal. A return to normal is impossible because of the absence of child's physical presence. Emma explains:

I'm [always] thinking 'oh my, if she was here we'd do this', or 'this would be [nice]', or 'her brother would be happy'...I just think of that. I guess most parents would. So, you never really go back to the normal that you had before. (pg 30, lines 21-23; pg 31, line 1)

Emma adds, "everything's changed in so many ways...It's just different. It's very different" (pg 64, lines 9, 11-12). Similarly, Kelly describes what normal meant before Sam's death and how normal no longer exists since his death:

Our normal was...Saturday, Sunday, Monday...soccer. Monday, Tuesday, Wednesday, Thursday, Friday...Tai kwon do for all the kids. We were so family. We were so tight with our kids. That's what it... was. Every night we were together. We did the sport....We would come home and have dinner...homework... bed...That was it. We were so tight as family. And now...we have none of that...Nothing is going to be normal again. (pg 112, lines 1-7; 34, lines 11-12)

A state of normal no longer exists. For a parent, the difference between life before and life after a child's death is staggering.

Aftermath of a Tsunami in the Soul

The magnitude of difference in a parent's life before and after a child's death can be likened to the drastic landscape changes that come in the wake of devastation following a violent storm. Some parents use this analogy to describe parental bereavement, equating this new state of being to a storm's aftermath. For Sara, parental bereavement is the aftermath of a tsunami in her soul which will exist for the remainder of her life (pg 9, line 5-6; pg 92, line 19). For Sara, Adam's death is a "tsunami in the soul" (pg 88, line 4-6; Sara, personal communication CaringBridge® journal entry, April 24, 2010, pg 25, line 4) and life after Adam's death is the "tsunami's aftermath" (pg 88, 11-17). Sara explains:

When I think of the word 'tsunami', there are automatic pictures that come to my mind seeing on the news. It is shocking to sit there and realize that this is happening and people are driving down the road and there is nothing they can do about it and their car is about to be swallowed up by the water...you just think of pictures of devastation and there's just nothing that you can do while it's happening and you think of just the tremendous loss and the things that happen so quickly to just change everything ...but there is an aftermath to a tsunami and ...we are still dealing with the aftermath and we always will be. (pg 88, lines 11-13, 17-21; pg 89, lines 2-5)

Sara's lived experience provides evidence that parental bereavement has no end point for many.

Peter offers a similar analogy explaining that Robert's illness was like being "in the middle of a storm" where "it's hard to see anything other than what you know is right in front of your face" (pg 37, lines 16-20). After the storm of Robert's illness (pg 36, line 16; pg 48, line 22; pg 49, line 1), came "the after effects" (pg 37, line 20; pg 49, lines 1-2) of his death. Kelly, too, speaks to after effects that followed in the wake of Sam's death, saying:

It's just destroying everything...it's just destroying...the entire family. Do I think we're going to break up? No, no, but, are we happy? I don't know how we're going to get that back...I'm at a standstill I think with everything – home, marriage, mother, career. It's at a standstill, it really and truly is. (pg 42, lines 9-12; pg 142, lines 13-15)

While parents are confronted with the tsunami's aftermath, those after effects often go unnoticed by others.

Invisibility

When parents are propelled to a new state of being following a child's death, their experience becomes invisible to most. Parents become shrouded by an ever-present, invisible fog that obscures them from view which adds to isolated nature of parental bereavement. Doris describes living amidst an invisible fog, explaining, "it seems to me that the cloud that I feel like I still live in, the fog that I still feel like I live in isn't visible to people" (pg 122, lines 21-22). I caught a momentary glimpse of this invisible fog firsthand as I sat in true presence with Peter during his first interview in a

restaurant. Our invisibility was palpable as Peter opened the doors to his lived experience of parental bereavement. Naturally, I wouldn't expect others to know why Peter and I were meeting. However, the separation between the two worlds of life's celebration and child loss was astounding. How can the sheer enormity of the life altering experience of a child's death be this invisible? While my first-hand glimpse was short-lived and nowhere near to being close to reaching the same depth and intensity, bereaved parents dwell in invisibility every moment of every day. The tsunami's aftermath goes undetected by others. Without a doubt, the invisible nature of this new state of being is an important part of what makes the lived experience of parental bereavement what it is.

Parents who participated in this study illuminate the essence of parental bereavement. To experience parental bereavement means to be propelled into a new state of being. Never before has the phenomenon of parental bereavement been clearly conceptualized in this way. While few have asserted that bereavement is the state of having lost a loved one through death (Barrera, D'Agostino, Schneiderman, Tallet, Spencer, & Jovcevska, 2007; Corless, 2010; Warren, 1997), this study illuminates parental bereavement as being an entirely new state of being that parents are propelled into immediately after the death of a child and in which they exist for the remainder of their lifetime. For parents who have experienced the death of a child due to cancer, to experience parental bereavement means to enter a new state of being in which they experience profound suffering, maintain the parenting relationship in the

presence of the child's absence through acts of remembrance and honor, experience a renaissance of self, and journey towards healing sustained by hope. A discussion of these essential aspects of parental bereavement follows.

Chapter VI

PROFOUND SUFFERING

Suffering: Incomparable, Indescribable, and Undeserved

Profound suffering is a key facet of the parental bereavement experience.

Suffering is “the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person” (Cassell, 1991, p. 24) and can exist with or without pain (Cassell 1982; Cassell, 1991). Ferrell and Coyle (2008) proclaim tenets of suffering to include the following: a) suffering is a loss of control that perpetuates feelings of insecurity, helplessness, and powerlessness to escape circumstances; b) suffering is often associated with loss; c) suffering is a very personal experience; d) suffering is accompanied by intense emotions such as sadness, anguish, fear, abandonment, and despair; e) suffering may influence how one views his or her own mortality; f) suffering prompts asking the question “why?” as one seeks to find meaning and answers that are unknowable; g) suffering is associated with separation from the world, a sense of loneliness, and strong desire to connect with others; h) suffering can be accompanied by spiritual distress; i) suffering is closely associated to pain; and j) suffering is likely to occur when a person feels voiceless and unable to share the story of his or her experience. These central tenets of suffering are reflected throughout parents’ lived experience of parental bereavement. The death of a child is an actual threat to a parent’s integrity as a person and continued existence. A parent’s

way of being in the world ceases to exist as it once did. Suffering is brought about by this very real threat to a parent's existence. The intensity of suffering which parents endure after a child's death is what distinguishes parental bereavement from other loss experiences. Suffering in parental bereavement is incomparable, indescribable, and undeserved.

Incomparable suffering. The intensity of bereaved parents' suffering is incomparable. This finding is consistent with existing literature on the unique nature of child loss (Cacciatore & Bushfield, 2007; Christ *et al.*, 2003; Hazzard, Weston, & Gutterres, 1992; Janzen, Cadell, & Westhues, 2004; Kazak & Noll, 2004; Kreichbergs, Lannen, Onelov, & Wolfe, 2007; McCreight, 2008; Milo, 1997; Sanders, 1980; Sirkiä, Saarinen-Pihkala, & Hovi, 2000; Rando, 1985; Wheeler, 2001; Wijngaards-de Meij *et al.*, 2008; Wilson, 1988; Znoj & Keller, 2002) and expands understanding of the incomparable nature of the parental bereavement experience. Emma explains what it is like to experience suffering following the death of a child, stating:

[It] is the worst, the very worst thing that can ever happen to you...sometimes different people that I have known have lost a husband and they say, 'Oh, I can understand', but they can't! There's no comparison over burying a husband or burying a child... There's no comparison. (pg 17, lines 19-23; pg 18, lines 2, 5-6, 8-10)

Kelly agrees that no loss compares to that of a child's death (pg 44, line 3), saying, "it's totally different for a parent who's lost a parent to try to compare that to losing a child...there is no comparison" (pg 43, lines 22-23). Joan also agrees that nothing compares to the loss of a child, saying "It's just such a different feeling to lose

a parent than to lose a child” (pg 30, line 12). Doris has also found this to be true when considering her own loss experiences, including the deaths of several extended family members and the death of her daughter, Cindy (pg 99, lines 16-23; pg 100, lines 1-2).

For Doris, one difference is that she got to a point where she felt a sense of comfort and acceptance with her previous losses. Doris explains:

There was just a level of acceptance, or comfort, that I got with my previous losses and I had a lot of past familial losses. I’ve always felt that at some point it stopped hurting quite so bad... this just doesn’t feel like that!. (pg 99, lines 18-20; pg 100, lines 1-2)

Another difference with past losses is that the absences of those people are not omnipresent in Doris’s daily life (pg 100, lines 6-7). Doris explains, “I know with all the losses over time...it wasn’t just in my face, and it feels now more in my face now more than ever” (pg 100, lines 6-8). Doris feels that the lack of a comparable experience to that of a child’s death (pg 81, lines 18-19; pg 99, lines 14-23; pg 100, 1-2) contributes to misunderstandings about parental bereavement (pg 81, lines 17-19). Doris says, “I don’t think that you can fully understand just how bad this hurts if you haven’t [lost a child]” (pg 58, lines 14-15).

Peter echoes the mothers’ experience, stating:

I never understood. There was a kid in school a couple of years before Robert that had leukemia and I’m like, ‘Oh my God, those poor parents’. And yeah...you did things and you donate to the cause and all that other good stuff...but...I don’t care how genuine your heart is or how much empathy you have as a human being, there is nothing that compares to it. (pg 23, lines 7-12)

Peter adds:

There are no words...I read somewhere that 'when a husband dies, she becomes a widow or when a wife dies, he becomes a widower, but what happens when a child dies? It is so horrible there are no words'. And if they gave it a name, I don't know if I'd be on board with it either. (pg 20, lines 9-13)

Since suffering in parental bereavement is incomparable, it cannot be fully understood by those who have not experienced the death of a child.

Indescribable suffering. Suffering in parental bereavement is indescribable. Peter explains, "it's an intensity that you can't put into words and can't explain...it's difficult to put into words because it's a constant" (pg 23, lines 16-19). Parents try to describe the intensity of their suffering using such terms as "locked in the gates of hell", "black hole", "the hole" and "the pit".

For Joan, the first five years after Joshua's death was "absolute... indescribable hell" (pg 8, lines 14-16; pg 32, lines 20-21, 23). Joan says she has been on a "horrible journey" (pg 26, line 4-5), explaining "I was in hell...I actually lived in hell...I was locked in the gates of hell" (pg 26, line 10). Joan recalls back to the day of Joshua's funeral, saying:

I would have paid anybody anything to be me. And even if I had millions of dollars to give to somebody they would not have wanted to be me for the day. It was just some place that nobody would want to be. (pg 62, lines 22-23; pg 63, lines 1-2)

Joan uses the term, "black hole" to describe this place of suffering (pg 10, lines 11-15). In the popular novel, *My Sister's Keeper*, Picoult (2004) writes "black holes are so heavy they absorb everything, even light, right into their center...no matter what you cling to, you wind up being sucked in" (p.11). This description of black holes

illuminates Joan's experience of suffering. The novel's storyline about a child diagnosed with cancer and her family resonates intensely with Joan, for she states "that's me, she wrote about me" (field note log, pg 5, line 7-8).

Kelly also attests to the presence of a hole when describing suffering. This hole is a physical, empty, and dark space that she cannot get out of (pg 58, lines 7-11; pg 90, lines 20-23; pg 91, lines 1,3; pg 92, lines 6-15; pg 94, lines 15-16, 21-22; pg 99, lines 5, 7; pg 104, line 20; pg 105, line 1; pg 116, line 14; pg 139, lines 1-3; pg 142, lines 13-15). Kelly explains exactly what this hole is like, stating:

It's definitely a hole...You want it to be bright up top again and...you can't [get out]. You want everything to stand still, but you are being slowly buried by just sadness, depression, just whatever it is and you feel like you can't get out. (pg 92, lines 6, 9-12)

Similarly, Emma describes a hole which she calls "the pit" (pg 44, line 23' pg 45, line 2). Emma explains, "you feel like sometimes you're down in the pit trying to climb out and you just can never, ever make it...there's nothing to help you" (pg 45, lines 2-4). Parents' incomparable, indescribable suffering is undeserved.

Undeserved suffering. Parents' suffering is so intense they would not wish it on anyone. Emma says, "It's something that you don't wish on your worst enemy, it's so horrible" (pg 18, lines 10-11). Peter concurs, stating:

Being in prison the rest of my life wouldn't be this bad. It wouldn't be a picnic, but it wouldn't be this bad...nobody should be in my shoes...I wouldn't wish this on Osama bin Laden. That's how bad this is. That's how bad this is. (pg 25, lines 6-10; pg 36, lines 18-20)

Joan echoes Peter and Emma's sentiments, stating: "nobody deserves to lose a child, not even the worst person in the world" (pg 26, line 7-8). Joan expresses empathy and sadness for Sajida Talfah Hussein, first wife of Saddam Hussein and mother of Uday and Qusay Hussein who were killed in 2003, because "[to experience a child's death] is the most horrible thing that I can ever imagine" (pg 26, lines 8-9). The profound suffering parents experience after the death of a child is accompanied by grief.

Grief

Grief is part of the overall parental bereavement experience. Grief and bereavement are distinct phenomena. Bereavement is a higher level concept, whereas grief is a lower level concept. Sara and Joan explain the difference. Sara states:

I think of grief as part of bereavement... something that you have to deal with because you are bereaved...I will always be a bereaved mother. I will always be a mother who has lost a child, but [the intensity of] my grief will vary...grief is...part of bereavement. (pg 107, lines 18-21; 108, line 2-4)

Joan explains that grief is "the emotional part of bereavement" (pg 77, line 8). This clarification is very important. Despite the growing body of grief and bereavement literature, conceptual ambiguity persists and invades nursing practice and education. From Sara and Joan's description, it is clear that grief and bereavement are not one in the same. Rather, grief is an essential aspect of bereavement. In other words, grief is "part of the collateral damage the shock and trauma of a child's death inevitably brings" (Farley, 2012, p. 15).

Multidimensional grief. Grief is the multidimensional response to loss (Doka, 2005). Parents who participated in this study report many grief responses. Pain, sadness, and longing are universal grief responses amongst these parents. In addition, parents report disbelief, anger, guilt, loss of control, loneliness, peace, numbness, fatigue, dulled happiness, envy, fear, and decreased concentration. Grief diversity contributes to the highly personal and individualized nature of parental bereavement.

Pain. Among parents in this study, pain is a universal grief response. Parents use various terms, such as “pain”, “ache”, “hurt” and “agony”, to describe the pain they feel after the death of a child. Emma describes her pain as “the awful hurt you feel with your heart, your soul, and every part of you, for the loss of a child” (Emma’s story, lines 1-7). Kelly says, “the pain is real...Pain is very real” (pg 45, lines 1, 9; pg 62, line 1-2). Kelly’s pain has both emotional and physical qualities. When Kelly feels pain, she is overcome with guilt (pg 46, lines 3-9; 14-15, 43; pg 47, lines 1-2, 4-8, 10-11), feels deep longing (pg 46, line 14), has difficulty breathing (pg 45, line 13), and loses her appetite (pg 46, lines 20-21). Kelly wants people to understand that it is impossible to experience the same intensity of pain without being in her shoes (pg 49, line 6-9).

Parents’ pain after the death of a child is a chronic, unrelenting pain. Emma speaks to the unending nature of pain based on 41 years of her parental bereavement experience, saying “the pain will never go away” (pg 74, lines 5-6). Sara concurs,

saying “pain does not lessen with time” (Sara, personal communication CaringBridge® journal entry, March 21, 2011, pg 11, line 4). Rather, pain intensifies with time. Sara found this to be true about her pain when she reflects on the pain she felt immediately after Adam’s death and the pain she feels now, two and one-half years later. Sara says, “you don’t really feel the depth of pain that you will feel later” (pg 22, lines 13-14). Doris also describes a constant pain that is similar to a chronic illness, stating:

The ache of [Cindy’s] loss is just constant. It’s like a chronic illness now...Initially, it was acute...it’s in everyone’s faces and...you could see acute injury... like when somebody had a broken leg...but...the long term, nobody can see that...they might see an occasional [sign] ...maybe you don’t walk as fast because you have arthritis and so you slow down a little bit, but the ache, the constant ache of her [loss]...just makes everything more difficult, every single thing! (pg 123, lines 21-23; pg 124, lines 1-5)

For Peter, the unrelenting pain is agony (pg 38, lines 12-16).

Parents seek relief from the pain. Doris says, “I don’t know how to make it not [ache]...I’d give anything to not have it ache so much!” (pg 123, lines 6-7). Kelly contemplates whether medications would alleviate her pain (pg 44, lines 20-23; pg 45, lines 1, 9; pg 58, lines 11-14, 19-21; pg 59, lines 1-4; pg 101, lines 7-8; pg 1-3, lines 3-6). Such pharmacologic treatment was not effective in managing Joan’s pain over the long-term. Joan’s doctor prescribed medications, such as Vicodin®, Valium®, and Ambien®, for the treatment of her pain soon after Joshua’s death; however, rather than decreasing pain, the medications intensified other grief symptoms and, as a result, Joan eventually made a purposeful decision to stop taking all medications that had

been prescribed for pain treatment (pg 4, lines 5, 10-11, 16, 18-19; pg 6, line 22-23).

In retrospect, Joan feels that medications were more effective in alleviating pain that her doctor experienced as a witness to her suffering, rather than her own pain. Joan explains:

I think [the doctors] medicated me so they wouldn't feel the pain. I became addicted to painkillers and sleeping pills and Valium...I would go to a doctor and that's the first thing he'd give me...He'd give me Ambien to sleep. He'd give me Valium. He'd give me whatever, anything...that would take the pain away from the doctor....looking back now, that's what I think...[the doctor] wouldn't feel the pain. And so my grief and my depression became worse...instead of better and I believe it is greatly in part due to all the drugs they kept giving me. (pg 4, lines 6, 10-16, 18-19)

Doris was also prescribed medications, including an antidepressant and anxiolytic.

Initially, medications helped (pg 120, lines 17). Now, however, Doris questions the effectiveness of medications because she still has intense grief feelings; yet, at the same time, she is very scared that her feelings would further intensify if she stopped taking medications (pg 119, lines 9-14, 22-23; pg 120, lines 12-15; pg 121, lines 12-16, 19-21; pg 121, lines 21-23; pg 122, lines 1-9). Doris explains:

I [am] really afraid. I will lose my mind...I'm kind of afraid not to take [medication] because I feel this crummy, but honestly I have taken it now for two years the same dose and I think to myself well...haven't I just developed a tolerance to it now?...it's such a low dose. It's the lowest dose that they prescribe...it's keeping you from feeling low. I feel...pretty a lot right now. If I didn't take it...would I feel so much worse? Or, should I feel? Should I just not take anything so that I just experience it all? (pg 122, lines 8-9; pg 199, lines 8-16)

The above examples reveal pain to be a universal grief symptom among bereaved parents. In addition to pain, sadness is another universal grief symptom.

Sadness. Sadness is a grief response experienced by all parents participating in this study. Commonly, crying is the physical release of sadness. Kelly cried a lot during the first two years of parental bereavement (pg 53, line 1; pg 104, lines 12-13; pg 138, lines 1-3) and says, “tears can come on any second...the sadness can come on any second” (pg 104, lines 12-13). Similarly, Joan cried all the time during the first six years of parental bereavement (pg 6, lines 7-8, 10-11; pg 31, lines 4-5; pg 35, line 6). Joan describes what crying was like for her using the following analogy of tears being like steam from a tea kettle:

You fill up the kettle with water and it makes tea, and it steams, and it keeps steaming, and steaming, and steaming until there's no water in the kettle anymore and then the kettle is empty and you got to fill the kettle up again in order to get more hot water to make tea. So that's what I felt like I did. [The] steam was like my tears. I just cried and cried and cried and then there was no more water in the kettle and I stopped and then someone filled up the kettle again. (pg 11, lines 15-18, 20-23; pg 12, lines 1-2)

Although crying is common, bereaved parents do not always cry when they feel sad. While Joan frequently cried in her early parental bereavement years, she has not been able to cry for the last eight years even though she desperately yearns for the physical release of sadness that crying brings (pg 6, lines 11-13, 15-16; pg 32, lines 11-12). Crying also was a way that Emma relieved her sadness in early parental bereavement years (pg 44, lines 14-23; pg 71, line 21); however, she is unable to cry due to medical treatment side effects that cause a decrease in tear production (pg 44, line 14-23). Emma explains:

I have no more tears. I get to the point that I want to cry so badly and I think that every once in a while a cry is essential, but I can't get the tears out. I think

that if I could just get a good cry out, but I can't right now! I can get sad...but I can't relieve it any right now. (pg 44, lines 17-23)

Just as not every bereaved parent cries when feeling sad, not all bereaved parents communicate sadness in explicit terms, such as "I am sad" or "I feel sad". For example, Peter expresses his sadness in different terms, such as "I'm done", "I was done", "I couldn't hold it", and "start to fall apart" (pg 3, line 16; pg 38, lines 15, 19; pg 42, line 13, 21). Similarly, at times, Doris uses such phrases as, "I am done" and "on the verge of losing it" to communicate her sadness (pg 102, line 11; pg 120, line 21).

The degree of sadness that bereaved parents feel can vary. Emma feels most sad when she is alone and says, "when I'm alone, it's there. It's always going to be there" (pg 45, lines 4-7). Sara's sadness intensifies during the spring, which brings a certain cruelty in the dichotomy between a typically joyful, lighthearted season and the sadness of grief. Sara explains what feeling sad in the spring was like for her:

Spring just seemed particularly cruel this year... it really did...like the winter was over, everything was coming to light, that time of year that people...look forward to...and it just seemed cruel that that spring was happening. It just seemed hard...it's just hard because that time of year that you think of as coming to life and the winter being over. (pg 95, lines 10-18)

Just as Sara experiences times of heightened sadness, Doris describes her sadness in terms of "sad periods" cycling between a few weeks of feeling less sad (pg 90, lines 1-3). Doris explains what sad periods are like for her:

I don't want to leave the house...during the day, I do whatever I have to do and I come home and I am done, done, done, done. [My husband] comes home and he's 'you wanna go out to dinner? You wanna go to the football game

here? So-and-so is playing volleyball, do you want to go watch?’ And, I don’t want to leave the cover of my cocoon. I would stay in comfortable sweatpants and be sadder than I already am. (pg 102, lines 9-16)

As much sadness as Doris feels two and one-half years into parental bereavement, anticipating sadness prior to Cindy’s death was worse (pg 120, lines 23). Doris explains:

Cindy was diagnosed the end of July and there was a point in November, the holidays were approaching and I just couldn’t stop. I couldn’t stop...I didn’t sit in a pool of tears, but...I felt on the verge of losing it. All I could think of is, it’s our last Halloween. It’s our last, last, last... it was way worse then. (pg 120, lines 17-23)

The above examples illustrate that sadness is a universal grief response among parents who participated in this study. In addition to pain and sadness, longing is another universal grief response.

Longing. Parents miss their children deeply and experience an intense longing that does not diminish with the passage of time. Sara says, “there’s just such a longing” (pg 77, line 5). For Peter, longing brings the feeling that “something is always missing” (pg 21, lines 6-7). Emma describes what it feels like to long for Dorothy, stating:

I would give anything in the world to have her back. I know she’s better off where she is, but I still miss her. I still miss her so much...I know that’s just...my mother’s love and...I know it’s impossible, but I still think about it and wish that we were all together again. (pg 55, lines 16-18; pg 56, lines 2-4)

Doris says about her daughter, Cindy, “I still miss her like the day she died, if not more so” (pg 71, lines 20-21). Echoing Doris’ experience that longing does not evaporate with time, Joan says “I do find myself feeling like those early bereavement

moments when I'm overcome with...longing for him" (pg 46, lines 8-10). Kelly explains just how deep a parent's longing can be:

I've often asked Sam does he want me to be with him. And I know for a fact that he would... say, 'what are you crazy Mom?!' So, I think that's just out of my own desperation...to be close to him, but I have two other children who are absolutely fantastic...that's selfish on my part. (pg 56, lines 19-23)

Kelly's longing must not be confused with suicidal ideation (pg 95, lines 3-4). Kelly genuinely misses Sam and she is coping with his loss, for she says, "Am I dealing with it, with Sam's loss? Of course I'm dealing with it! I'm alive" (pg 59, lines 4-5). In addition to universal symptoms of pain, sadness, and longing, parents experience a variety of other grief responses.

Anger. Most parents feel angry. There are many different things that cause a parent to feel angry. Among the four parents who express anger, most are angry at people who complain, God, and the lack of advancement in childhood cancer research. Three parents express anger with other people who complain about their own healthy children, such as with their children's school or sports performance. Doris conveys her anger saying:

People will complain about something normal and if I'm talking to myself I'm saying, 'Are you kidding me?!' But that's their reality and that's their life and I would have been upset about things like that before. I get mad when people complain about their kids. I wish I had your troubles, which is really...not a very nice way to be! They have their own issues and everybody's things are difficult for them. (pg 84, lines 9-15)

Two parents express anger at God for allowing their child's death. Joan conveys her anger saying:

I was mad at God for a very long time. [I'm] still mad at God. I think I have a different God in my life today than I used to have in my life... how could this happen to my child? What did I do to deserve this? What did he do? Just someone tell me. I never got an answer. (pg 21, lines 18-21)

Two parents express anger about the lack of substantial advancement in childhood cancer research. Peter conveys his anger, stating:

I have an iPad. I can sit anywhere in the world, type on my iPad, and look up stuff, and email you, and email me, and look up the latest price on the most ridiculous gadget in the world, but 30 years have gone by and all they can do for DIPG is give him an MRI?!... And yeah,...breast cancer is bad and...prostate cancer and...pancreatic cancer, they're all bad. They are all bad. Not one is worse than the other, but it's just odd how so much money is generated for cancer research and of *all* [emphasis added] the monies, *all* [emphasis added] the monies, less than 0.5% goes to...*all* [emphasis added] [childhood] cancer research! And...I think it's funny,... we sell Viagra by the millions because, *hey!* [emphasis added], men are popular and they're willing to spend the money. But we haven't gone more than a couple of feet further in 30 years for childhood cancer? I think there is something wrong there. But then again there is something wrong with everything...We all complain about our taxes... but...we pay the taxes because what are we going to do, give up the house? And...a parking ticket is now \$50 when it used to be \$25 and what do you do, not pay it?...I think there should be more awareness...and I'm just as guilty as everybody else. Two years ago, I had no clue there was a thing called 'DIPG'. I had no clue that this existed. Alright, its only 200 cases a year in the U.S., give or take,...so how bad could it be? It's not a 100,000 breast cancers, so of course marketing is going to go where the customers [are]. (pg 3, lines 21-23; pg 4, lines 2-23)

Peter adds:

The reality of it is these are all...neuro-oncologists...they're the smartest in the room...even the dumbest among them is the smartest in the room. However, combined they are the best guessers in the country. They're taking the information they have at hand...and making the best guess they can of what they're doing... the steroids and the gaining 40 pounds and not being able to balance. So let me break your leg and give you a 50 pound pack to carry on your back. Oh, and by the way, you're going to have 2 little dogs running around your feet to make you dizzy too. You know, like, I'm really not impressed over 30 years of the same thing. (pg 11, lines 13-17)

Similarly, Doris conveys anger, stating:

I was so flabbergasted that nobody could do something [to treat DIPG] in 30 years...These are our kids that we profess to...care so much about and...yet we have nothing?! We've come up with nothing?! We've been on the moon! ...Look at the survival rates with...prostate cancer...Look what we know diagnostically about breast cancer. We treat breast cancer as if it's one of 50 types of breast cancer. It's not just breast cancer!...*How can this really be this way?!*[emphasis added] ...I'm still amazed that we're so backwards that we fund less than 4% of...our national budget for cancer research [that] goes to kids!...I'm just livid at the presentation that was made by the head of NIH...I just want to scream because when you read his remarks and when he's presenting his remarks they make it sound like pediatric cancer is all but cured and [has] an 85% survival rate...it infuriates me! (pg 49, lines 7-18, 23; pg 50, lines 2-4; pg 130, lines 10-11, 13-16)

In addition to being angry about the lack of significant advancement in childhood cancer research, being angry with people who complain about their own problems, and being angry with God, there are various other things that stir feelings of anger including the following: a) other people's assumptions that life is back to normal, b) family members avoidance of conversations about the child and what the parent is going through, c) no longer fitting in with former friends, d) once-supportive people wandering away, e) the fact that the child died, f) the suffering that the parent is now left to endure, g) the fact that life continues on without his or her child, and e) unnecessarily restrictive hospital policies that negatively impacted the child's quality of life.

Anger is understood to be a common emotional grief response among parents following the death of a child (Corless, 2010) and often directed towards health care

personnel (Cimete & Kuguoglu, 2006; Aho, *et al.*, 2006), God (Aho *et al.* 2006), or even themselves (Aho *et al.*, 2006). Findings from this current study expand present-day understanding. Findings illustrate that there is a wide array of sources parents' anger can be directed towards a wide array of sources.

Although most parents express anger towards various sources, not all parents do. For example, Sara says "one of the interesting things about us is that we have never really been angry... you're not angry, you're not...mad at the world, you just miss your son" (pg 9, line 16-21). Similarly, while Emma knows some parents who are angry with God for their child's death, she feels differently (pg 35, lines 5-21; pg 80, lines 22-23; pg 81, lines 1-5). Emma says, "I never did get angry with God! I never once got angry with God...I know some people say God took your child. I don't believe that. God did not want me to lose my child. It's just this life" (pg 35, lines 16-17; pg 80, lines 22-23). The fact that anger is not experienced by all parents demonstrates that grief responses vary among bereaved parents. The varied nature of grief contributes to highly individualized nature of parental bereavement.

Loneliness. Feeling lonely is another common grief response experienced by most parents. Four parents conveyed feeling lonely. Feeling lonely is not the same as being physically alone. Feeling lonely is a feeling of being emotionally separated from others due to the fact that they either do not comprehend what it is like for a parent after a child's death or do not verbalize their own grief feelings for the loss of the child. Emma explains, "it's not just being alone physically, it's...in your mind

you just feel [alone]” (pg 23, lines 17-18). Sara adds, “it’s a hard place to be. You feel alone, but it’s not like you really are alone... the people around me know that I’ve lost a son... but they don’t know what it’s like to lose a son” (pg 82, lines 16-19). Joan concurs, saying “it is a very lonely place to be because I am there all by myself. There is nobody else there with me...not even him” (pg 48, lines 6-8). Kelly also describes becoming overwhelmed with a feeling of loneliness (Kelly, personal communication, May 24, 2013, lines 11-16).

Envy. Many parents convey feeling envy. Three parents feel envious of friends who have children. Kelly provides an example of one instance when she felt envy:

We’re at the pool. Sam loved to swim. I see his friends... I don’t want to admit it, but [I feel] jealous...but how can you say that about other people’s children? You can’t. They’re all...precious...[but] that’s your initial feeling, absolutely...They still have their child and I don’t... I don’t. (pg 123, lines 20-21; pg 134, lines 1-3, 7, 9, 11)

Doris, who experienced a similar feeling of envy, explains:

There will be an activity and most of our friends...are going to be with their kids and I find myself getting jealous of my girlfriends...and that is a silly way to feel but I actually think I feel that. It’s like, ‘well, I don’t have any kids to hang out with, so you shouldn’t either’. (pg 83, line 20-22; pg 84, line 1-2)

Feeling envious is a difficult feeling for parents to endure. Doris explains:

It is embarrassing. I am not a good friend anymore...I feel these things that I would have chastised myself in my former life for and I kinda do now...I don’t even think I would have thought of some of the thoughts that go through my head now. (pg 84, lines 4-8)

Decreased concentration. Many parents experience decreased concentration.

Activities that require concentration, such as completing work-related tasks, reading a book, and getting dressed are difficult. Joan describes having difficulty concentrating in her earlier parental bereavement years:

I'd wake up in the morning and I'd put on all black, but it wasn't necessarily because I liked all black or because I was in mourning...I didn't want to have a choice. I had no concentration. I couldn't think of something to wear. (pg 51, lines 19-23)

Concentrating is also difficult for Doris at times. Doris explains:

I just watch mindless television. I watch more TV than I watched in my entire [life] ...I swear!...I can't focus long enough to get through a book, even that 'Fifty Shades of Gray' that everybody said was so naughty and fun, I couldn't... get through it. (pg 117, lines 12-16)

Peter finds it is difficult for him to concentrate at work explaining, "I made bad, stupid mistakes. I don't read the email and I hit send" (pg 22, line 12). For Kelly, a decrease in concentration feels like living in a fog. Kelly explains:

The fog [is] just not [being] clear...a dull...ache without pain. You know something is happening in your life...and it's a dull ache. That's a really good explanation of what I call my fog...you know it's there, but it doesn't hurt...it's one of those silent pains. (pg 109, lines 4-8)

Fatigue. Some parents feel fatigue, which they describe as not having enough energy to get through the day. Kelly describes her fatigue, saying:

Just to put my head up was...very, very difficult...I mean even now, I don't really want to do much. There's not much energy in me...I feel like a couch potato most nights. I got no desire to do anything. I don't 'cause I'm so tired. (pg 24, line 21; pg 25, lines 1-2; pg 89, lines 16-18)

Lack of sleep is a contributing factor. Doris usually can fall asleep, but awakens frequently (pg 106, lines 4-5). She says, “You don’t get enough sleep. You’re not getting enough exercise. It’s just...this evil cycle that is very difficult to climb out of” (pg 106, lines 13-14). Kelly has also experienced this fatigue cycle, whereby fatigue leads to decreased physical activity which contributes to weight gain, which negatively affects her overall health (pg 101, lines 5-7; pg 103, lines 1-3). Kelly does not like feeling this way and is searching for ways to break the fatigue-decreased activity-weight gain cycle because otherwise, as she says, “I am going to get myself all miserable” (pg 101, lines 6-7).

Range in happiness. Some parents experience a range in their level of happiness. Happiness may be absent. When happiness is absent, a bereaved parent is burdened by a heavy weight. Kelly explains what the absence of happiness is like for her:

I’m so tired of waking up heavy, so tired of waking up just generally not happy. There’s a heavy feeling all the time. You do your regular things, don’t get me wrong. You get ready, you get your breakfast...but there’s... this heaviness...There is no joy anymore. (pg 58, lines 14-18)

The absence of happiness for Kelly means every day is “a constant battle” that requires much effort to do what needs to be done (pg 34, line 19; 107, line 7). Prior to Sam’s death, Kelly maneuvered through her days with relative ease. Now, heaviness hinders her ability to navigate each day. Kelly explains:

When I get home the first thing I do is...put my head down and that was never, never the way I used to be. [I] used to get up at 5 or 6 o’clock in the morning and [at] 12:30 [I’d be] laughing. (pg 107, lines 8-11)

A parent does not choose to be unhappy after the death of a child. Rather, a parent yearns to feel happy. Kelly wants to feel happy again (pg 142, lines 10-11) and is searching for “something that will make me happy that includes Sam” (pg 119, lines 18-19).

Happiness may be dulled. When happiness is dulled, a bereaved parent is unable to fully experience pure happiness. Doris explains what dulled happiness is like for her:

I can't say that I don't feel happiness and that I don't see joy or that I don't laugh or that I don't smile but,...it's not the same. It's not the same kind of happy...I feel like I can't fully experience the joy or the happiness or the love that I once did. (pg 63, lines 18-19, 21; pg 85, lines 1-2)

Doris gives the following example: “I'm happy, but I would be happier if Cindy was alive...we had a good weekend, but wouldn't it have been more fun if Cindy was with us. I find myself still saying or thinking things like that” (pg 85, lines 9-12). An inability to feel the pure happiness is not a result of parental guilt or parental choice.

Doris explains:

I don't worry about her thinking, ‘Holy cow, mom didn't love me enough. It's been two years and seven months and she had a glass of wine and she was happy!’ I know that's not what it is. It's just really hard to feel that pure happiness. (pg 86, lines 4-7)

Rather than parental choice, it is the presence of the child's absence that hinders parents' ability to feel pure happiness. Doris explains how, in spite of her and her husband's best efforts to celebrate his birthday as a happy occasion, her happiness was dulled on account of Cindy's loss. Doris states:

We had to force ourselves to do something...to even mark that it happened...that was a little hard. So I put on my big girl pants and I...got my husband to go out to dinner and...got him new running shoes and a couple of things that we wanted...it wasn't the cake and wrapping paper and that kind of birthday....I think we had a nice evening [but]...every single thing is just marked by that loss....I don't know how to... continue on with my life and feel...happy anymore. I don't know what that feels like" (pg 86, lines 9-10; pg 87, lines 1-7; pg 100, lines 4-6)

While happiness may be absent or diminished for some parents, a greater level of happiness is possible and may help to counteract intense feelings of sadness for others. This has been the case for Emma. Emma is able to feel happy at times. For example, the birth of her great-granddaughter four days before her daughter's birthday brings Emma happiness (pg 74, lines 1-6). Emma shares:

[The birth of my great-granddaughter] will help me not be so sad over my daughter's birthday. It's like something that will counteract that...I'll have a happy thing happening... I guess sometimes it takes a lot of years for it to...straighten out and then all of a sudden you find there's so many nice things happening to help, even though the pain will never go away...it's just so good to have nice, happy things to happen too. (pg 74, lines 1-6)

Emma's happiness brings a reprieve from her sadness, although it does not eliminate her pain.

Guilt. Some parents convey feelings of guilt. Parents who expressed guilt most commonly feel guilty about causing their child's illness and subsequent death. Joan feels guilt over the fact that she was unable to prevent Joshua's death, explaining: "fathers and mothers are supposed to save their children...I couldn't save him...and it's all about now, if onlys...if only I did this, if only I did that" (pg 14, lines 16-18).

When a parent cannot protect his or her child from harm, a parent may internalize blame. Joan blames herself for Joshua's cancer and subsequent death.

Because Joan wasn't able to save Joshua, she blames herself. Joan says:

What did I do? Did I let him fill up the gas tank with his dad?...little boys, they get outta [*sic*] the car and wanna [*sic*] help dad pump gas. Maybe he...breathed in too many fumes by standing at the same height as my gas tank. Or, maybe, that electrical wire outside my house, maybe that gave it to him? Or, maybe, my worst fear was true...I'm such a defective person that here I have a child who has...a real serious problem now. It's something that I did that caused him to have this cancer...I don't know what it is, but I'm sure that I'm to blame for it...I'm sure that it's something that I did...I thought that there has to be something that I did...I still have days like that...for the most part it has passed... but I still read about things in the newspaper – this causes cancer, broccoli causes cancer...whatever and I think, 'Oh, did he eat that? Did he take that? Did he do that?'...You can read about anything, anything causes cancer, if it tastes good or whatever, it all causes cancer...so, I don't know...what I could have done to stop it. (pg 12, lines 10-12, 14-16; pg 13, lines 5-9; pg 14, lines 2-8)

Peter also blames himself for Robert's death, saying:

I feel that I must have done something really bad to deserve this...I must have done something really bad to deserve this. That's how bad it is...There is nobody that deserves this and that's why I wonder...I must have done some really bad things...that's where I'm at. (pg 25, lines 6-9; pg 36, lines 21-22)

In addition, bereaved parents may also feel guilty for other people's sadness that is elicited when learning of the child's death and for being unable to feel true happiness for their surviving children. Peter explains what the latter is like for him, saying:

My daughter was in the eighth grade. She graduated from grammar school. She applied to two high schools. She got in two high schools. She got money from two high schools. And I'm very proud of my daughter, make no mistake, but I couldn't help but think 'wow, what would Robert have done?!' And that doesn't say a whole lot about me... the guilt that I feel about not even being to be totally happy for my daughter is kind of tough...it's not really so great. (pg 12, lines 5-10, 20-22)

Fear. Some parents convey feelings of fear. They fear that their surviving children will die too. Kelly has experienced panic attacks as a result of the trauma of Sam's death. Kelly shares:

I've had a few panic attacks...I don't know if that's because [since] we lost Sam, [I'm afraid] that am I going to lose my other children...I've become more neurotic, more so than the regular parent would do probably, but...if I was to lose my second child...that would be it. I'd be done. There's no way I would go through two, no way. (pg 109, lines 10-16)

Peter also expresses fear that his surviving child will die too, saying "I worry about my daughter all the time...will she have something catastrophic happen to her?" (pg 21, lines 15-16). Parents also fear that their child will be forgotten. Kelly says, "the whole thing that scares me is Sam not being remembered and being forgotten. That's not by accident, not by accident because it's never by accident, but you know, because the years just roll on" (pg 88, lines 21-22).

Other responses: disbelief, numbness, loss of control, and peace. In addition, individual parents express feelings of disbelief, numbness, loss of control, and peace. Sara describes feeling an initial sense of numbness (pg 77, line 3) and "tremendous peace" (pg. 22, line 12). For Sara, peace is comforting. Peace is noteworthy in that it is the only grief response reported that was comforting in nature. Although Sara's sense of peace remains 2.5 years later, it coexists with deep pain (pg 22, lines 12-15). Joan feels disbelief that Joshua died after being diagnosed with cancer (pg 10, lines 12-15; pg 12, lines 9-10; pg 14, lines 8-9; pg 29, lines 13-14; pg 30, lines 1-6) and that the life continues after Joshua's death (pg 11, lines 7-9; pg 31,

lines 5-8), saying “I couldn’t believe the sun rose every morning without my son being on this earth (pg 52, lines 13-14). Joan can only believe that Joshua died “in small increments” (pg 29, line 14). Joan shares this feeling of disbelief with her husband, whom Joan says “I think that [my husband] is in total denial that he died...that he’s not coming back” (pg 14, lines 10-13). The trauma of a child’s death can cause parents to feel a loss of control. Joan did whatever she could in attempts to regain control after Joshua’s death. Joan describes what this was like for her:

I would scrub my kitchen floor...I got my toothbrush and...I would scrub. I would look for control in anything I can get control, whether it was cleaning my house, or cleaning my pocketbook...I’d want my purse to be like clean and organized ‘cause I felt I’d have some control over something ‘cause my life was so out of control. (pg 12, lines 4-8)

Pain, sadness, longing, disbelief, anger, guilt, loss of control, loneliness, peace, numbness, longing, fatigue, dulled happiness, envy, fear, and decreased concentration are among the constellation of grief responses that parents experience throughout parental bereavement. It is important to note that parents’ grief is a direct manifestation of the trauma associated with their child’s death and not the result of any choice made on the parents’ part. Doris explains:

This is not a choice! [emphasis added] I do not wake up every morning and say, ‘I’m going to feel like garbage!’, ‘I’m going to be tired today’...*that’s not how I am!* [emphasis added] It’s how I feel a good percentage of the time, but I don’t feel that I am choosing this. I don’t feel like I am choosing to be...grumbly or whatever” (pg 118, lines 16-21)

Parents’ grief responses are consistent with existing literature that conceptualizes grief as the normal emotional, cognitive, behavioral and physical

response that is associated with the loss of a loved one through death and which varies between individuals in the intensity, duration, and manner in which it is expressed (Christ *et al.*, 2003; Corless, 2010; El-Jawahri & Prigerson, 2007; Zhang, El-Jawahri, & Prigerson, 2006). Just as the type of grief responses vary, so too does the intensity of those responses.

Grief intensity. The intensity of grief fluctuates over the course of a parent's life. Grief is more intense on some days and less intense on others, but it never disappears. One and one-half years into parental bereavement, Peter says, "some days are better than others and some days are just tough" (pg 3, line 6-7). There is no reprieve from grief, for as Peter says, "*it's every day* [emphasis added]...every day is different...every day is hard...sometimes I'm just grateful I can get out of bed in the morning" (pg 22, lines 6-9). Doris also has found that although "some days [are] better than others" (pg 56, line 1), her grief is more intense in the second year (pg 100, lines 2-3; pg 121, line 14). Doris offers a few reasons for this, including feeling numb in the first year post loss (pg 99, line 13), expecting to "feel like crap for the first year" (pg 99, line 14), and diminishing support in the second year (pg 100, lines 8-22; pg 101, lines 1-17, 19-23; pg 102, lines 1-6).

In the early years of parental bereavement, Joan's immense grief was all-consuming. Joan explains:

It invaded every aspect of my being... it encompassed every cell in my body...every cell in my body was grieving for what had happened...every breath I took was about my grief. It was bigger than my life. It was bigger than my world. It was everywhere. I couldn't paint a room in my house, or

change anything. I just didn't have the strength. I just had the strength to grieve in and out. (pg 51, line 19, 23; pg 52, lines 1, 4-8)

Over the past 15 years, Joan has found that her grief has "softened" and became "less intense" (pg 77, lines 17, 19) to the point where "every cell wasn't hurting" (pg 52, line 3). Joan tries to compartmentalize her grief so it is not all-consuming (pg 51, line 18).

Grief will always be a part of Emma's parental bereavement experience. Forty one years in parental bereavement, Emma says:

I don't let the grief overwhelm me anymore. It's there. It's inside of me...I don't think there is any way to completely get rid of it...you would think that after all these years [grief] would have lessened, but it hasn't. Sometimes, it's just still unbelievable. I miss her so much... it's not as fresh as it was a first, but...it doesn't go away...certain times in the year...hurt more...than other times...as the years go by, it has to lessen some, but at certain times it doesn't. (pg 5, lines 4-6; pg 65, lines 19-21; pg 75, lines 2-5)

Grief intensity ebbs and flows throughout a parent's life.

Parents' grief intensifies at random or when encountering a specific trigger.

On some days, grief is like a rogue wave that comes out of nowhere and crashes over a bereaved parent. Peter explains:

There's no rhyme or reason... it sneaks up on you... that's the agony of it. You think everything is going to be fine...and then... you start to fall apart...I don't get it, but it sneaks up on you. (pg 3, line lines 8-9; pg 38, lines 12-16)

On other days, specific situations trigger more intense grief.

Triggers are documented in the chronic sorrow literature (Eakes *et al.*, 1998; Burke *et al.*, 1999). Chronic sorrow is "the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with ongoing disparity

resulting from a loss experience” (Eakes *et al.*, 1998, p. 180). Disparity is the gap between the desired relationship and the actual one. The disparity is of an ongoing and unresolved nature, whereby the parent experiences the loss in bits and pieces over time. Consequently, parents experience more intense grief periodically. Disparity is exacerbated by trigger events. Trigger events are “those circumstances, situations, and conditions that bring the negative disparity resulting from the loss experience clearly into focus” (Eakes *et al.*, 1998, p. 181).

What may be a trigger for one parent may not be for another. For bereaved parents, triggers include the presence of their child’s absence, associated memories of their past reality, and role changes within the family unit. Parents in this study describe a multitude of triggers.

Anniversaries of the child’s birth and death trigger intense grief. For Doris, Cindy’s birthday triggers more intense grief than her death anniversary. Doris explains:

[Cindy’s] birthday...is excruciating for me, at least it has been the past two years...Sometimes it seems like the days working up to [it] are worse than the actual day itself...I was in a tizzy, just an emotional kind of thing,...in the days just before [her birthday], but on the actual day of her death, it isn’t [like that]. I felt better. I wasn’t as sad. (pg 60, lines 4-9)

Doris contrasts her experience with that of her dear friend whose five year old son also died of cancer a few months after Cindy’s death. Whereas Cindy’s birthday triggers intense grief for Doris, her friend’s own birthday intensifies grief more so than her son’s birthday. Doris shares, “her child’s birth date, [Tommy’s] birthday, is not a

hard day for her. Her own birthday is enough to make her want to poke both her eyes out and jump off a cliff” (pg 59, line 23; pg 60, lines 1-2). This is one example of how grief triggers can vary among bereaved parents.

Another example of varied grief triggers can be found within Doris’ and Sara’s parental bereavement experience. Whereas Doris experiences more intense grief on Cindy’s birthday, Sara experiences more intense grief on the anniversary of Adam’s death. Sara explains:

The day of his death is harder. It is. That whole day is just [hard]...Adam died very peacefully and so there are some beautiful memories that I have of that day, but it’s still [hard]. You are not focused on the day that he came into the world. You are focused on the day that he died...that is hard. That is harder...we tend to do better with his birthday than we do with the end of the year, at the time that he died, because we tend to focus on...the good parts of his life. But it is still hard, because at the end of the day...he is still not here. So even though we do so much to make it a positive day, at the end of the day you still just feel this emptiness. (pg 29, line 23; pg 30, lines 1-6; pg 94, lines 13-17)

Similarly, Emma has found that Dorothy’s death triggers more intense grief. Emma shares:

I take a little downward step when I know November is coming...The entire year she is on my mind. I never stop thinking about her and loving her, but it seems like November...even after all these years, it is still hard... this time of year it’s just fresh as it ever was. (pg 55, lines 2-3, 10-12, 16)

Just as birth and death anniversaries can trigger grief, holidays such as Mother’s Day, Father’s Day, Thanksgiving, and Memorial Day can trigger a greater intensity of grief.

For example, Sara explains why her grief intensifies near the Memorial Day holiday:

[Memorial Day] automatically draws your mind to cemeteries and cleaning up graves and that kind of thing. We live on and we put our patriotic pins on a

little vase that we have next to his marker...it makes me think about children who are fighting a war that they didn't choose to fight. (pg 78, lines 7-12)

Likewise, certain seasons of the year can trigger more intense grief. For example, the spring season, which for many is a happy time of year, is a particularly difficult time of year for Sara. She says:

Spring just seemed particularly cruel this year... it really did...like the winter was over, everything was coming to light, that time of year that people...look forward to...and it just seemed cruel that that spring was happening. It just seemed hard...it's just hard because that time of year that you think of as coming to life and the winter being over. (pg 95, lines 10-18)

The trigger of seeing the child's favorite foods can make grocery shopping excruciating for a bereaved parent. Joan describes what this was like for her:

I couldn't go to the supermarket myself for a few years...He loved crackers [so] I couldn't walk down the cracker aisle. I couldn't walk down the cereal aisle because he loved cereal. Aisles that if I walked down, I would just completely fall apart and I would be there probably for hours crying, hours! I was a mess. (pg 53, lines 19-23; pg 54, line 1)

For many parents, watching their child's friends achieve developmental milestones, such as graduating from Cub Scouts, going to prom, entering and graduating high school, getting married, and having children, triggers very intense grief. For example, Joan says, "I'll see one of my son's friends...now they're getting married or having children. These are all the things that won't be for my child...I feel very sad about that" (pg 47, lines 17-19). Doris relates a similar experience:

It's hard to watch the kids [Cindy's] age. I have a hard time watching them do the things she should do...it's sad for me to watch these kids at prom...or homecoming, or even confirmation last year at church. Cindy should have been confirmed at that time. (pg 56, lines 11-12; pg 66, lines 8-11)

Several parents experience intense grief when they see a boy or girl who looks like their child or when they see another parent with a child. Peter tearfully describes what it was like for him to experience this latter trigger:

I was in the supermarket and there was this kid there with his dad...he was holding a bunch of items and...struggling with them...they were at the register and he was helping his dad...The dad didn't look like me. The dad didn't look my age...the boy didn't look like Robert, could have been somewhere around his age. I was done. I just couldn't even hold it. (pg 3, lines 10-12, 14-16)

Subsequent losses can also intensify a parent's grief. For example, Emma's grief intensified after her 30 year old nephew was killed in an automobile accident (pg 13, lines 12-15, 17-23; pg 14, lines 1-2; pg 26, lines 3-6; pg 76, lines 12, 16-19). Emma recalls:

I got hysterical...[my therapist] said it opened up old wounds from my daughter...I couldn't imagine why, but out of my brother's five children, the one who was killed was born a couple months after Dorothy in the same year and it was just so bad. (pg 13, lines 19, 22-23; pg 24, lines 1-2)

Emma's grief was also intensified on the bitter cold day of her mother-in-law's funeral. Emma explains:

The first [winter funeral] I had to go to was my mother-in-law...it was so cold... it was like the day...that my daughter was buried...it was so strange because from the time my daughter died and the time my mother in law died, it was years! I had been to four or five or maybe six funerals between with family and all and every one of them was a summer or spring [funeral] and...I never had that experience until this one... it was so hard and it was so cold. (pg 29, lines 11-12, 18-19; pg 56, lines 14-18, 20)

For some parents, returning to the hospital triggers flashbacks which, in turn, trigger greater grief intensity. Peter experiences flashbacks whenever he sees an ambulance parked outside the hospital's emergency department (pg 8, lines 19-22; pg 9, line 1).

Peter explains, “whenever I’m at the ER...the ambulance outside sparks that memory all over again. It’s similar to smelling something and it brings you back to being seven years old in your grandmother’s house. It’s exactly like that” (pg 8, lines 19-22). The sight of the ambulance brings back the memory of Robert’s diagnosis day with a vengeance, thereby triggering greater grief intensity. Kelly explains just how difficult it was to return to the hospital where her son was treated:

I remember going to the hospital first time after Sam had passed away...just tears, but I knew I had to do it. I knew I had to do it. I did it. I did it. I went to see my friend who was still there...It was very difficult...And [on] the last visit...my friend’s son was transferred into Sam’s room. That was incredibly tough and I just remember being in her arms and saying ‘have him transferred’. I said ‘please have him transferred!’ ...I knew Sam had passed away in that room. (pg 54, lines 22-23; pg 55, lines 1-2, 9-17; 19-23; pg 56, line 1)

For some parents, the sight of the hospital from a distance is enough to trigger intense grief. Joan describes what it is like for her to drive by the hospital where her son was treated:

I cover my head and everyone tells me when I pass the hospital so I don’t have to...see it. And I just think, maybe, one day I might have cancer and I’ll have to go down there and won’t that be a laugh because I’ll have to go there and I’ll have to face the building and I’ll have to see [it]...I’ll have to deal with it, but thank goodness I don’t have to deal with it today. (pg 15, lines 8-13)

For Joan, Peter, and Kelly, the hospital triggers intense grief. For other parents, the hospital provides relief from intense grief. Soon after Adam died, Sara found comfort in visiting his hospital room. Sara explains:

At the beginning, I used to love to go back up to the hospital...my daughter and I would like to go into the room where he died...I just think we felt like we were with him. Where we were when we had last been with him. (pg 13, lines 20-23)

The familiar hospital room was a place where Sara felt connected to Adam and provided her temporary relief from intense grief.

While familiarity can be comforting for some parents, changes within the once familiar hospital environment trigger intense grief. In this case, changes in the hospital environment represent a drastic break in the connection bereaved parents have with their child. Sara experienced intense grief on a return hospital visit when she discovered that Adam's picture, which he had drawn on a hallway window during his hospitalization, had been washed away. Sara explains what this was like for her:

It shocked us that his picture had been washed off ...the windowed mirror. All four of us were there and it was very difficult for all four of us... it hurt! It seemed like they were just trying to get rid of his memory.... it was something that was very difficult for us....we didn't know that it was going to happen and it was just shocking to us...it almost seemed like we were washing away his memory so that we could bring in new kids to make new memories. (pg. 26, lines 1-2, 4-6, 12-16)

The explanation that Sara received as to why Adam's picture had been removed was because it was a source that triggered the hospital staff's grief:

I think Adam had been there so much that I think there were people who were having a hard time walking by his window every day, seeing it. I think they finally, they washed it, basically to be able to function. That is what my understanding is of what happened. (pg 26, lines 8-11)

Two and one-half years later, Sara says she understands and is no longer upset about it because as she states:

That is the way life is. That is the way it is. But it is hard to think of it. It's hard if you are just hit square in the face with it at a time like that when your grief is so deep...it almost felt...like, '*Why did you do that to us? You leave everyone else's window up!*' [emphasis added] (pg 27, lines 1-2)

The glass window meant so much more to Sara than just paint on a window or a fun activity for a child to do during hospitalization. Adam's picture was a tangible piece of Adam's existence. Sara provides the following written expression of her experience in her journal:

Our memories of Adam's Superman window, Kenny's rainbow window and Mario's soccer window are a stark reflection of our reality. There was a time we could see the brushstrokes and touch the paint just as we could see our boys and touch them; but life has gone on without them. New young artists have painted pictures on the windows, and new people walk through the hallway every day--people who don't know about the paint that has been washed away forever. We have no choice but to tuck away the memories of the windows in our minds just as we keep the memories of the boys in our hearts. (Sara, personal communication CaringBridge® journal entry, May 4, 2010, pg 21, lines 30-39)

Sara provides this example of how seemingly minor changes, as perceived by hospital staff, can actually be very significant changed for a bereaved parent and trigger intense grief.

Large hospital changes can also intensify bereaved parents' grief. For example, Doris' grief exacerbated when the hospital where Cindy was treated closed (pg 44, lines 1-2). The reason Doris' grief intensified with the closing of the former building was because that was the physical space where she shared her lasts with Cindy. In a written expression of her experience which she eagerly shared, Doris writes:

I have an attachment to Children's Hospital. Even now, almost two years after my daughter's death, I long to see it. It is at Children's Hospital that my daughter had many lasts. The last time I saw her smile. The last time she wrinkled her nose when her brother tried to kiss her cheek. The last time she pointed at me and indicated that I should go eat. The last time she would ask

to be turned so that I could lay with her and smell her sweet scent. The last time she called my name. (Doris' article, Children's Hospital newsletter, Spring 2012, paragraph 4)

For Doris, the hospital's closing weakened her attachment to Cindy's lasts. For both Sara and Doris, the hospital is a place they feel connected to their children. When hospital changes fracture that connection, grief intensifies.

Parents describe many other situations that acutely trigger intense grief, such as remembering things their child said or did, watching videos of their child, doing weekend errands their child once enjoyed, doing new activities that their child never experienced, seeing people they haven't seen since before their child's death, being unable to talk about their child or their grief feelings with others, watching a television show with a storyline that mirrors their own experience, being confronted with the presence of the child's absence, and recalling traumatic memories of events that occurred during the child's illness. In regards to the latter, remembering events related to the trauma of the child's cancer diagnosis and death can be distressing and all consuming. When remembering becomes distressing, a parent may actively employ techniques that halt recall in attempts to minimize acute exacerbations of grief. For example, Joan describes using a technique she terms *playing the tape backwards* to stop recall of remembering excruciatingly vivid details that surrounded Joshua's illness and death. The inherent difficulty in recalling sequential events in reverse order forces Joan's thoughts to stop, providing her some relief from re-living traumatic memories. Considering all of the examples described, the diversity of grief triggers

parents experience is evident. Kelly sums up grief triggers in this way: “I guess I miss him so deep that anything...could trigger me off, absolutely trigger me off” (pg 138, lines 1-3).

The intensity and duration of grief concerns parents. Doris worries that her grief will be unending, saying:

I just want to know how long this... pain lasts... People say and I read things and I talk to parents...whose children have been gone 8-10 years...and I hear pretty much the same thing. That...some days are better than others. Some events will trigger...a sad thing or a sad time and then there will be times when it's better. I still hear [this] from these parents...there wasn't a whole lot difference with the feeling I have than with someone from 8.5 years [post loss]. So then that worries me...Will I feel better in eight years? Or will there not be a difference? Or is any difference better? (pg 91, lines 10-16, 20-22; pg 92, lines 1-2)

Some parents worry that a decrease in grief intensity means they are forgetting their child. Peter's grief feels ever-so-slightly less intense now, than it was immediately after Robert's death and he worries if it's because he is forgetting Robert (pg 47, lines 1-6). Doris shares Peter's fear. Doris explains:

I keep wondering how long it's going to be difficult. I want to know if there is an end to the depth of this loss and then, at the same time, you worry that if you stop feeling this way that you will have forgotten her and that she didn't exist, and *she did!* [emphasis added] (pg 67, lines 16-19)

Doris hopes the intensity of grief will lessen over time. This is evident when Doris says, “I hope at some point I have a place where...I'm able to live with a little less sadness” (pg 71, lines 4-7).

Conceptualization of grief. Parents do not believe that grief is a series of stages that culminate in acceptance. Joan says, “[the] seven stages of grief...it is a

bunch of *crap!* [emphasis added]” (pg 29, line 15-16). While she knows that “he’s not going to come back” (pg 46, line 20), Joan cannot accept Joshua’s death. Joan says:

I go to the cemetery and I can barely look at the headstone and I can’t believe it every single time I look at the head stone. Every single time I go up there, *every single time I go* [emphasis added], I’m in disbelief that my son [died] and that his name is carved on the stone. *How could it be?* [emphasis added]...Especially in the beginning, I fool myself into [thinking] he’s at summer camp. He went away for the weekend. He’s gonna call me any minute...I used to fool myself. But every time I go to the cemetery and look at that headstone, I just shake my head. I cannot believe it. I cannot accept it. I don’t think I’ll ever accept it. I don’t know how this could have happened to my son... I lost my mother. I lost my father. I don’t think they’re ever coming back. I accept that. (pg 29, lines 22-23; pg 30, lines 1-8, 10-11)

Doris says the following about grief:

I took a death and dying class at college and I got to do the whole...Elizabeth Kübler-Ross thing...and I understand how you can vary between stages and...I just wonder what acceptance would feel like...when I think about accepting it, it’s almost like I’m saying that it’s ok that she is gone...*it’s not ok that she’s gone!* [emphasis added] (pg 85, lines 19-23; pg 86, lines 1-3)

Doris also reflects on the proposal to include prolonged grief as a mental disorder in the fifth edition of the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (2013). This proposal has not been without controversy. Prigerson et al. (2009) advocate for the recognition of *prolonged grief disorder* as a mental disorder in DSM-5 and document diagnostic criteria validity. Yearning plus five of the following nine symptoms must persist for at least six months after the loss: a) confusion about one’s role in life or diminished sense of self; b) difficulty accepting the loss; c) avoidance of reminders of the reality of the loss; d) inability to trust others since the loss; e) bitterness or anger related to the loss;

f) difficulty moving on with life; g) numbness; h) feeling that life is meaningless; and i) feeling stunned, dazed, or shocked by the loss. Study participants (N=291), the majority of whom were elderly, white women who experienced the death of a husband, were interviewed once within the first year post-loss. While Prigerson et al. (2009) suggest further study in more diverse populations over time would be beneficial, they postulate that findings can be generalized to most bereaved persons and conclude that sufficient evidence exists to justify prolonged grief disorder as a mental disorder. Others advise caution.

Rando et al. (2012) advocate for continued dialogue in the field. Rando et al. (2012) identify a need to not only broaden conceptual understanding of grief but also to explore how circumstances of the loss and the relationship lost influence the overall bereavement experience. Ultimately, the DSM-5 committee did not reach consensus for adding *prolonged grief disorder* as a mental disorder (Doka, 2013). Instead, the bereavement exclusion, which was present in DSM-4 and stated that major depression should not be diagnosed in individuals experiencing symptoms within two months after the death of a loved one, was eliminated (Wakefield, 2013). Elimination of bereavement exclusion has generated concern that clinicians are now more likely to diagnose major depression in individuals who experience grief after the death of a loved one and thus, foster conceptualization of grief as a pathologic illness in need of medical intervention (Friedman, 2012). After reflecting on her own lived experience of parental bereavement and following discussions with other bereaved mothers, Doris

questions the appropriateness of conceptualizing grief in this way. Doris ponders, “whether we should be under clinically depressed or is grief different than clinical depression...can they coexist?” (pg 119, lines 5-7). Doris is concerned that the normal, lifelong grief response to the trauma of experiencing a child’s death and enduring a lifetime without the child’s physical presence is deemed to be pathologic.

Paternal vs. maternal grief. In spite of a growing body of grief literature, considerably less is known about fathers’ grief than mothers’ grief. While bereaved fathers experience emotional and physical grief responses (Aho *et al.*, 2006), it has been purported that fathers experience grief that is less intense and of shorter duration than mothers (Barrera *et al.*, 2007; Kavanaugh, 1997; Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steinneck, 2004; Lang, Gottlieb, & Amsel, 1996; Lang & Gottlieb, 1993; Li, Hansen, Mortensen, & Olsen, 2002; Li *et al.*, 2003; Murphy *et al.*, 1999; Rando, 1983; Vance, Boyle, Najman, & Thearle, 1995; Wijngaards-deMeij *et al.*, 2008; Wing, Burge-Callaway, Clance, & Armistead, 2001). On the contrary, findings of this study suggest otherwise. Peter reports the same intense grief responses as the mothers including sadness, guilt, anger, decreased concentration, longing, and fear. Furthermore, Peter has encountered similar triggers which further intensify his grief. Peter’s intense grief is not unlike that experienced by other bereaved fathers.

Farley (2012), a bereaved father, author, and founder of the Grieving Dads Project, explains the sheer intensity of his own grief following the death of two children over an eighteen-month period stating, “I couldn’t stop hurting. I didn’t just

cry – I physically wept inside. There were times when there were no tears, and it felt like I was convulsing internally” (p. v.). Apple (2008), also a bereaved father and author, describes the triggers that intensify his grief stating, “The first missed birthday was a nightmare, and I had assumed it would be rough. What surprised me was how the future birthdays and holidays also affected me” (p. 98).

Apple (2008) also experienced random intensification of grief about which he states, “No one told us about-nor were we ready for-the sneak attacks that would come after we lost our son. By sneak attacks I mean those things that seemed to pop up when we were least expecting them” (p. 99). Farley (2012) and Apple (2008) illuminate the intensity of Peter’s grief which fluctuates at random or in response to triggers. While further study of fathers’ experiences is no doubt warranted, no major difference between Peter’s description of grief and that of the mothers emerged from this study. Care should be taken not to generalize fathers’ grief. Thoughtful consideration should be given to the fact that parental grief responses are variable. The diversity of grief responses, grief intensity, and grief triggers contribute to the individualized, highly personal nature of the parental bereavement experience.

Things People Do or Say Cause Additional Suffering

What people do or say cause added distress for parents after the death of a child; thereby, increasing suffering in their parental bereavement experience. All parents describe situations in which people have said or done certain things that acutely exacerbated many of the grief responses previously discussed. This acute

exacerbation of grief can occur at the particular moment in time that the situation occurred and also at a later date when reflecting back on that situation. These situations fall into the following five main categories: a) when people manage or explain; b) when people avoid; c) when people question; d) when people complain; and e) when people compare.

When people manage or explain. When people attempt to manage the parent's bereavement experience or explain a reason for the child's death, parents become distressed. All parents have encountered this situation. A multitude of hurtful comments have been hurled at parents in attempts to fix or explain their experience, including the following: "God only takes the good ones"; "God needed him in Heaven"; "God need an angel"; "God knows best"; "He's in a better place"; "God doesn't give you more than you can handle"; "Everything happens for a reason"; "That's why you adopted her because otherwise...her life wouldn't have been what it was, so there's a reason she came to you"; "You had 11, or 10 good years with him"; "You got to have him for eight years"; "You're lucky to have him for as long as you did"; "At least you got to know him, you didn't have a miscarriage and didn't get to know him"; "Well, you have your memories"; "What a gift he was"; "Better to have loved and lost, then never to have loved"; "God gave you two more children"; "You have other children"; "You have three other children"; "Which one is better, losing a child quickly or losing a child after an illness?"; "I know how you feel, my grandmother died last year"; "She doesn't need you to do anything for her"; "She's

where she's happy and she doesn't need that"; "Time will make it better"; "Time will take it away"; "You'll get over it"; "Are you over it yet?"; "When your heart is open, healing will come"; "If you had enough faith, you would have been healed"; "It's time to move on"; "Get over it"; "You have to get on with your life"; and "Pick your head up and move on". These misguided comments arise from ignorance.

People simply do not understand what the parental bereavement experience is like; for if they did, comments like these would be unheard of. Parents explain what it is like to hear such comments in the hopes that people will better understand the additional suffering they impose. Doris explains:

The most frustrating part is the fact that other people who haven't lost a child seem to think they have all the answers and want to put a time on it, or I should be doing this, or I should be doing that, or I should be grateful that I have my son, or that I should be grateful that I had 12 years with her, or and that implies to me that *I'm not grateful* [emphasis added]? And that I didn't enjoy the 12 years that I had? Which is all a load of *crap* [emphasis added]!...I'm your average run-of-the-mill...mom. I did all the mom-things with my kids. I did all the mom-things...my kids are...my life. (pg 56, lines 3-11)

Doris is angered when people say "pick your head up and move on" (pg 118, line 15), as if she had a choice about her feelings. Doris says, "I just want to scream at that kind of stuff" (pg 118, lines 15-16). When Sara was told, 'when your heart is open, healing will come', she says:

I don't think anyone can look at us and say that our hearts are closed...I think if you've just never gone through anything like this, it's just hard to have a comment like that from someone who doesn't feel what you're going through. (pg 9, lines 16-20)

A friend once told Kelly, “get over it and get on with your life”, about which Kelly says:

How wrong is that [emphasis added]?....Needless to say, she didn't really become a friend after that. I knew she couldn't have been in her right mode [sic] 'cause no one would ever say that that was normal. The first week of losing your child you're supposed to [get on with your life?]....I wasn't going to make her feel bad then. I just was not in the state to argue or fight. Done. I will say hello to her if I see her 'cause as far as I'm concerned she is a nosy person anyway. But, that's people for you, huh? I will never forget that. (pg 35, line 15; pg 123, lines 1, 3-5, 9-12)

Doris stresses, “Tell your nurses, tell them never to say that ‘everything happens for a reason’. That is a... pet peeve...I don't think it happened for a reason...I see things differently” (pg 69, lines 17-18; pg 70, lines 7-8). Peter says:

I got people with children who are young adults now say, ‘What a gift Robert was’ and ‘You're lucky to have him for as long as you did’. So, *when's a good time* [emphasis]?! Is it *10* [emphasis added]? Is it *20* [emphasis added]? Is it *30* [emphasis added]?...really, *really* [emphasis added]?! And there was no saying anything because anything I would have said would have been wrong” (pg 19, lines 21-23; pg 20, lines 1-2).

Peter would rather people not say anything at all and says, “for me, it's better not to say anything than to open up your mouth insert your foot.... there are no words” (pg 20, lines 7-9).

When people avoid. When people avoid contact with the parent or avoid talking to the parent, parents become distressed. The majority of parents have encountered this situation and as a result, experienced additional suffering. People's actions toward Joan cause her to feel hurt and isolated. For example, to avoid having any contact, people have purposefully avoided her by walking down a different aisle

in the supermarket (pg 9, lines 2-5, 9-12) or by crossing to the other side of the street (pg 58, lines 13-16). Joan says, “people who haven’t lost children think like it’s a disease that’s catching... they thought it was catching whatever it is that I had” (pg 56, lines 12-13, 15-16).

Doris and Peter also feel a sense of isolation when the supportive presence of others wanes. People’s inability to give Doris the support she needs contributes to her sense of isolation. For example, Doris says:

When I have a really bad day, when I reach out to...people, they don’t respond or they respond in some canned way like, ‘I know it’s hard’, ‘I’m really sorry’, and for whatever reason it is just not enough. (pg 100, lines 15-18)

People would rather text or email, rather than communicate verbally with Doris because “they don’t want to hear my voice” (pg 100, line 20). This further adds to her isolation. Peter gives an example of a supportive friend who wandered. Peter’s good friend, Keith, canceled their dinner plans at the last minute (pg 47, lines 12-23). This was very hard for Peter. Peter says, “am I mad at him? No, I can’t really be mad at him” (pg 47, line 20). Trying to understand why his friend canceled, Peter determines it’s because their connection was Robert. Without Robert, Peter can’t relate to Keith and what his child is doing in school or sports (pg 47, lines 21-22). Without Robert, Keith can’t relate to Peter (pg 47, lines 22-23). Peter likens it to, “when you get a divorce and you really, really, really loved your sister-in-law and talking to her, but you can’t now and that’s because what connected you is no longer there” (pg 47, lines

15-17). Peter and Keith's friendship was centered on their children. Without Robert, their friendship wanes leaving Peter further isolated.

When people avoid talking with parents about their child and their experience, feelings of sadness, anger, and isolation increase. It makes Doris sad and angry when people don't talk about Cindy (pg 67, lines 19-20; pg 92, lines 4-5, 7-8, 10-15, 19-23; pg 93, lines 1-8). Doris shares the following example:

Christmas Day...the first Christmas after she died, my parents, my sister, and her husband were here and I swear it was like a four or five hour time period where not one of them mentioned her name. I mean, *how can that be* [emphasis added]?! (pg 67, lines 20-23)

Although Doris may cry when people talk about Cindy (pg 92, lines 4-5), it is worse when they don't because as Doris explains, "*it's as if she didn't exist* [emphasis added]!" (pg 92, lines 7-8). Doris perceives this to mean that Cindy has been forgotten (pg 92, line 19) and Cindy wasn't important (pg 92, line 20; pg 93, line 5).

When people don't talk about Cindy not only do they fail to remember Cindy, but also they fail to acknowledge Doris's experience. Doris explains:

Maybe it's selfish part on my part [but] I want them to remember how bad this hurts. Some days you just want to wear a sign on you that says, '*You think your life sucks, you should try burying your child* [emphasis added]!'...I wish people could understand that sometimes the tears when people don't talk about her are worse than the tears when people do talk about her. At least I get a chance to...talk about her. (pg 92, lines 13-15; pg 93, lines 3-7)

Emma shares a similar experience. After Dorothy's death, Emma's family never spoke of her (pg 5, lines 15-16; pg 15, line 21; pg 28, lines 3-4; pg 62, lines 10-

11; pg 76, lines 3-8). Emma's brother didn't talk to her about Dorothy until 27 years later when his own son was killed in an automobile accident. Emma recalls:

I was with my brother that day...every time I looked at him, he had tears...I went over to him and he was...on the side of the bed...I...put my arms around him and we starting talking...I brought up Dorothy and he said, 'You know, when I was pallbearer that was the hardest thing I ever had to do in my life'...I didn't find that out until all those years later...I just wish that people would have [talked about her]. It was like they liked wanted to pretend she never existed...you want people to know that she did exist and she was and is *still* [emphasis added] my daughter. (pg 14, lines 3-13)

When Emma is unable to talk to others about Dorothy and her grief, she feels abandoned alone in the world (pg 15, line 20). She describes just what it's like for her when people don't allow her to talk:

It was horrible. It was like being alone in the world. I mean, even my family, that's how it was back then I think. I don't know if they really thought it was better...that's the way my husband thought, that if you didn't think about it then it would go away and you could continue on but life never, *ever* [emphasis added] goes back to the same point as it was. You're really never completely the same again...I think...the more people can [talk, the better]. I know the thinking is 'don't bring it up because it will make her sad', but the sad thing is...it's always on your mind. They're not reminding you of anything that you don't already know in your mind...She's my daughter. *I want to remember* [emphasis added]....People did not want to mention her name or bring her up...people don't want to make you sad. Well, that's silly because you are already sad and you want to talk about it" (pg 15, lines 20-23; pg 16, lines 1-7; pg 71, lines 18-21)

Even if Emma herself mentions Dorothy, people are reluctant to talk about her. Emma says, "most people I know, they are uncomfortable if I bring it up" (pg 19, line 7).

Sara too was left feeling abandoned without the support of family and friends.

Sara explains:

Right after those funeral services when everybody left, we had a lot of people leave on one particular day and then I think we had some families that were with us for a day or two longer and then everyone was gone. And it was so hard to be all of a sudden just completely alone...our lives had just changed so much I don't think we knew exactly where to begin. (pg 22, lines 18-23)

When people question. When people ask questions, parents become distressed. The majority of parents have encountered this situation. People commonly ask the following questions: a) how are you?; b) how many children do you have?; c) do you know if your other children have cancer too? These questions do nothing to soothe parents' suffering. Rather, these questions cause additional distress. Doris finds it difficult to respond to the "ridiculous, 'How are you?' question" (pg 67, line 2). Doris says, "people really don't want to know how you are" (pg 67, line 11). Doris tries to ignore this question because she understands most often it is just used as a greeting (pg 104, lines 13-20); however, she says "I'm just feisty enough that I want to go, 'How the *you-know-what* [emphasis added] do you think I am?" which is not fair... I'm just feisty enough to be hateful sometimes so I really have to work at it" (pg 104, lines 14-17).

People will casually toss out the question, "How are you?", in passing and the answer that comes to Sara's mind but is never verbalized is:

Well, I finished treatment for breast cancer...had a 2-3 month reprieve before Adam's brain tumor progressed and things got intense, eventually lived in the hospital with him for five months and two weeks, took him home and set up our own pediatric intensive care unit in the living room, enjoyed three good months before things began to deteriorate, and held him in my arms as he took his final breath on earth...I'm feeling fine. How about you?" (Sara, personal communication CaringBridge® journal entry, August 6, 2010, pg 16, lines 12-18)

Kelly says people have asked her “stupid questions”, such as “Do you know if [your surviving children] have cancer too?” (pg 79, line 1, 8-9) to which she answered, “I hope not...*I hope not* [emphasis added]!” (pg 79, lines 11-12). People often ask parents how many children they have. While no harm is intended, it is a difficult question for a bereaved parent to encounter. Emma describes what it is like when someone asked her this question for the first time:

For a minute [I was] dumbfounded...the first time...they asked me how many children I had,...I didn’t know how to answer at first...finally, I said I had two children because that is the *truth* [emphasis added]! Because *I did* [emphasis added]! And I *still do* [emphasis added]! I am still a mother of two children. (pg 45, lines 7-13, 19)

Emma couldn’t say she had just one child because, as she explains, “it’s like saying well she’s never been here” (pg 45, line 20-21). Emma adds, “people don’t do it to be mean, they just don’t know. But I would warn mothers to be aware of that question because... it’s going to come up” (pg 46, lines 14-16).

Joan handled this question just like Emma did, saying she has four children when asked: her oldest child, Joshua, and youngest twins. When pressed as to their ages, Joan provides a range “my oldest is 23 and the twins are 12”. If pressed further as to the age of her other 4th child by someone she doesn’t know, she simply says “he was born in 1986”. She doesn’t tell them that Joshua died because she doesn’t want to “depress them” (pg 27, lines 18-23; pg 28, lines 1-18). Joan says her husband “never mentions his son who died” (pg 28, line 8) and this sometimes leads other people to

wonder about “this extra child that one parent talked about” (pg 28, line 9-10). Doris answers in the same way and says:

I do feel compelled to say that I have two kids....Depending on the situation, I can usually read if I’m feeling like I want to share our story or if it’s appropriate to share our story or not and, based on that, I can maneuver the conversation. That hasn’t been a problem for me...I just move on with it...and almost always, people will say how sorry they are and I know that they are sincere. And so, I’ll say ‘thank you, that means a lot’ and then...move on...the [person] doesn’t really necessarily want to hear the whole story. (pg 73, lines 19-22; pg 74, lines 1-5; pg 74, lines 5-6, 8-9)

When people complain. When people complain about their own children or trivial matters, parents become distressed. The majority of parents have encountered this situation in parental bereavement. Parents experience additional anger when people complain about a variety of things, such as their children’s school or sports performance, general stresses of parenting, minor health ailments, their car becoming dirty, their clothes becoming soiled in the rain, and a limited selection of color options at the automobile dealer. Joan expresses her anger when people complain about their children’s sports performance by saying, “your son, your daughter didn’t make the travel soccer team, my son is dead. It doesn’t *get* [emphasis added] much worse than that!” (pg 11, line 5-7). Doris, expressing anger when people complain about their children, says “I get mad when people complain about their kids. I *wish* [emphasis added] I had your troubles” (pg 84, lines 11-12). Kelly, expressing distress when a friend came to pay respects after Sam’s funeral but refused to get out of her car because she didn’t want her clothes to get dirty, says:

I remember her coming over to the house and it was a rainy day and she didn't want to get out of the car, because she didn't want her shoes and her pants dirty. I said to her, 'well your car's dirty'. [She said], 'No! No!' She was very upset that her car was now dirty because of the wet dirty puddles...hmmm, hmmm, they're all false. (pg 63, lines 20-23; pg 64, line 1)

Peter, also angered by complaints, says:

I'm also very callous or a big jerk. Like, *really* [emphasis added]? *That's* [emphasis added] your problem? You want to trade?...They only had red Cadillacs! They didn't have blue ones? Oh boy!... And.... don't tell me about how you're struggling with your kid because he's being 12, 14, 21...I'll trade ya. I'll trade you in a minute...yes, I understand that it's frustrating. I understand that. (pg 19, lines 6-10, 19-20)

Every day frustrations such as these do not even come close in comparison to the experience of a child's death. When people burden bereaved parents with their frustrations and complaints, it only causes parents additional distress on top of their grief. Additional distress contributes to suffering in parental bereavement.

When people compare. When people compare their own loss experience to that of the parent, parents become distressed. Some parents have encountered this situation in parental bereavement. Although done without apparent malice, comparisons of loss experience cause bereaved parents to feel additional pain. For example, Emma states:

People that I have known [who] have lost a husband,... say 'Oh, I can understand', but *they can't* [emphasis added]! There's no comparison over burying a husband or burying a child... There's no comparison... things like that are just hurtful more than anything... That is really, really something that I don't like because they've never [lost a child]. If you've never been there, you can't possibly make a comparison like that. (pg 17, lines 21-23; pg 18, lines 2, 5-6, 8-10)

It's also upsetting for Doris when people make comparisons. For example, someone once compared the experience of having an autistic child to Doris's experience. Doris says:

Sure, that's a huge loss...but their kid is still alive. Certainly there is a whole different level. I think there is grief involved in their [situation] too...you must grief the absence...of things that you had thought for the future. So I see some comparisons, but I still keep thinking I would rather have [Cindy] alive. (pg 81, lines 21-23; pg 82, lines, 1-2, 4-5)

Doris offers a reason as to why people make such comparisons: "they want to connect. They want...you to know that they care, so convert to their own situation" (pg 58, lines 8-10). However, in doing so, people unwittingly cause parents additional distress on top of the pain that already exists in their grief. Emma wishes people could understand this and act differently because comparisons cause so much additional hurt (pg 18, lines 5-6, 8-13, 18-21). Emma states, "things like that are just hurtful more than anything... That is really, really something that I don't like because they've never [lost a child]. If you've never been there, you can't possibly make a comparison like that" (pg 18, lines 5-6, 8-10). The additional hurt caused by such comparisons contributes to suffering in parental bereavement.

In summary, people's words and actions can cause bereaved parents additional distress; thereby, increasing suffering in parental bereavement. This finding not only fills a gap in current literature, but also illuminates an opportunity for education. Educating people about what not to say or do to a bereaved parent may prevent

additional distress and further suffering. People must understand that their words and actions have negative impact on the parental bereavement experience.

Health Care Providers and Care Processes Cause Additional Suffering

Bereaved parents remember the care that they and their child received during their child's illness. When care is flawed, it becomes a source of parental distress not only at the time of occurrence but also after a child's death. Parents' recall of distressing care encounters augments suffering in parental bereavement. Most parents describe such encounters. Hallmarks of distressing care encounters are poor communication, insufficient information, exclusion from child's care, and differences in care goals. Isolated reports of care encounters involving a lack of caregiver continuity, treatment delays, and inflexible hospital policies also contribute to additional distress after a child's death. Further, bereaved parents experience additional distress as a result of abandonment by their child's caregivers and as a result of their own health care providers' behaviors.

Poor communication. Poor communication is a hallmark of distressing care encounters that contribute to bereaved parents' suffering. Parents recall care encounters in which their child's health care providers either communicated insensitively or did not communicate clearly with one another. Upon recall of these encounters after a child's death, bereaved parents experience distress. It is easy to understand why when one considers the many examples of insensitive communication

that parents share. Doris recalls the following care encounter when a physician made a very insensitive comment at the time of Cindy's DIPG diagnosis:

You walk in as a parent and...you're newly diagnosed and so you believe you can still get the miracle. You still believe your child can beat it. You're trying to be realistic, but you believe it and [the doctor] looks at your child and says, 'Hey, you know what this means? You can do whatever you want with school this year! *It doesn't really matter* [emphasis added]!' (pg 26, lines 5-7, 9, 14-19)

The inherent implication being that it really didn't matter how Cindy did in school because she was going to die. The physician's insensitive and thoughtless comment remains seared into Doris' memory two and one-half years after Cindy's death.

A comment such as this is an example of a breakdown in a core concept of patient- and family-centered care, respect and dignity. The Institute of Patient- and Family-Centered Care (2013) describes the core concept of respect and dignity as follows: "Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care" (retrieved from <http://www.ipfcc.org/faq.html>). In this care encounter, the physician failed to consider what Cindy understood about her diagnosis of DIPG (pg 27, lines 10-17). Doris explains, "Cindy doesn't really know how to take that yet because Cindy really, until her bleed in February, she didn't want to talk about dying...her concept was 'when I get better'" (pg 27, lines 10-13). The physician also failed to consider the value Doris and her family placed on school (pg 26, lines 20-22; pg 27, lines 1-2, 4-7). Doris explains, "we're teachers and up until that point we went to school unless you were

puking or bleeding...that's just what you do...we're go-getters. We just keep moving on. That's how we roll" (pg 26, lines 20-22; pg 27, lines 6-7).

Doris provides a second example of a care encounter in which a health care provider communicated insensitively. Doris was just awakening from sleep in Cindy's hospital room, when a resident physician entered and bluntly communicated the news of Cindy's death. Upon entering the room, the resident physician immediately stated, 'Mrs. Smith, Cindy is dead' (pg 53, lines 20-21). When Doris recalls this moment two and one-half years later, she is clearly upset and says:

I remember... thinking, 'Seriously [emphasis added]?!'...yeah, we're going to work on that part of your training, ok?!' I'm sure I could have been the very first person she ever had to say that too. I remember thinking, 'you are not wearing a gray coat [like the attending physicians], so you need to leave'. (pg 53, line 21; pg 54, lines 1-3)

Communicating the news of a child's death to a parent in this manner is a failure to uphold two core concepts of patient- and family-centered care: respect and dignity, and information sharing. The Institute of Patient- and Family-Centered Care (2013) describes the core concept of information sharing as follows: "Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making" (retrieved from <http://www.ipfcc.org/faq.html>). The manner in which the resident physician communicated the news of Cindy's death was done in such a way that was not affirming, or supportive, for Doris. Communicating the news

of Cindy's death in this manner is also a failure to uphold the concept of respect and dignity in patient- and family-centered care. To enter the child's hospital room in the middle of the night and bluntly tell a parent, who is just awakening from sleep, that her child is dead is an example of communication being done without respect or regard to a parent's dignity.

Peter provides a third example of a care encounter in which a health care provider communicated in an insensitive manner. Peter recalls the following encounter which remains very distressing one and one-half years after Robert's death:

I called hospice up the day after [Robert] passed to say we won't be needing you. Well, the lady who spoke was very angry and annoyed with me for calling 911. [She said,] '*Why did you call 911 for? What did you do that for?* [emphasis added]' [I said,] 'Just come and pick up your stuff, we're done...I'm telling you my son died. Somewhere in your chart you know that he is 11 years old'. I don't care if he was 111, he's my son. You know? [She said,] 'What did you call 911 for? You know you're not supposed to call 911. You're not supposed to call 911. You're supposed to call us'. [I said,] 'Come and get your stuff'. So yeah, there is a need for pediatric palliative care. (pg 30, lines 17-23; pg 31, lines 1-4)

In this care encounter, the health care provider failed to uphold the concept of respect and dignity in patient- and family-centered care. To reprimand a father for not immediately calling hospice when his son died is an example of insensitive communication being done without regard to honoring the family's perspective and dignity.

These three examples illustrate how recall of care encounters that involve insensitive health care provider communication cause bereaved parents to experience additional distress years after a child's death. In each of these encounters, a

breakdown in patient- and family-centered care core concepts occurred. There is opportunity for health care providers to communicate more sensitively and hone their practice of providing patient- and family-centered care consistently with each and every care encounter. For, in doing so, perhaps in the future, bereaved parents would no longer experience the added distress that comes from recalling insensitive communication encounters with their child's health care providers. If this additional distress was prevented, perhaps it might help soothe some of a parent's suffering in parental bereavement.

In addition to encounters involving insensitive communication, bereaved parents also recall care encounters in which there was a lack of clear communication between health care providers. These encounters are frustrating for parents not only during a child's hospitalization but also upon recall after a child's death. Recall of such encounters contributes to bereaved parents' distress. Parents provide three examples of care encounters in which there was a lack of clear communication between health care providers. In the first example, Kelly expresses continued frustration with the lack of communication amongst Sam's health care providers more than one year after Sam's death. Due to a lack of communication, resident physicians who cared for Sam on the weekends were less knowledgeable about his medical condition and treatment plan than physicians who cared for him during the week (pg 69, lines 1-5, 9-10; pg 127, lines 14-19, 21; pg 128, line 1). Kelly recalls a specific encounter when a weekend resident questioned her, "You brought him in February

27th? How come it's now September that you only figured out that he had a brain tumor?" Kelly replied, "Say what?" The resident continued, "Well, that's the paperwork. Their saying that you didn't bring him in until September" (pg 69, lines 1-5).

Due to a lack of clear, accurate communication between health care providers, the weekend resident not only lacked the correct facts but also judged Kelly based on those incorrect facts. The fact that Sam was diagnosed with medulloblastoma only five days after the onset of very subtle, nonspecific symptoms was unknown to this resident. This was distressing for Kelly at the time and remains so over a year after Sam's death. Kelly says, "the lack of communication... sucked... over the weekend... horrible" (pg 69, lines 9-10).

In a second example, Doris expresses continued frustration over the lack of communication amongst Cindy's health care providers and explains what it was like for her to have to tell Cindy's story repeatedly to many nurses and doctor:

You have to tell your story 1500 times...that's one thing I wish people knew or could do a better job [with] ...when you go in and...they come in and it's the floor nurse or it's the ER nurse or whoever it is and you tell your story. Then, she leaves or he leaves and then 10 minutes later, resident #1 comes in and they want the same thing. Now, I really want them to be informed, but somehow by the 3rd or 4th time that I've told you that... I am all done!...Maybe it's really necessary for me to tell my story 10 times because it helps that doctor or nurse to make a better decision. I don't know, but I remember that being incredibly frustrating" (pg 39, lines 15-19, 21-22; pg 40, lines 1-4)

Two and one-half years after Cindy's death, Doris still feels very frustrated when recalling this type of care encounter. Doris wants nurses and doctors to understand that parents' perceive their repetitive questioning as a sign that they are not listening (pg 40, lines 6-8, 10) and hopes that newer technology will help facilitate expedited access to patients' medical history and information (pg 39, lines 22-23; pg 40, line 1).

Peter provides a third example of a care encounter in which a lack of communication between health care providers led to their lack of knowledge about end-of-life care goals. When Peter's son, Robert, was brought to the emergency department in respiratory distress near end-of-life, a resident physician opted to consult with a pediatric neurosurgeon in preparation for surgical treatment. Since soothing Robert's symptoms to maximize comfort was the primary goal at this time, the possibility of such invasive treatment frightened Peter. Peter expresses the frustration he felt at the time and still does to this day more than one year after Robert's death when he says:

Had a student doctor in there saying, 'Well, we'll talk to the neurosurgeon'. For *what [emphasis added]?! 'Well, maybe surgical intervention'*. Go wait in the hall. Alright, go wait in the hall. I understand what you're saying...his attending [physician] was next to him but, like with all doctors, one doctor isn't going to say anything about the other doctor. No matter how big of a screw up I think he is, he's a doctor. He's good, ok. So, there was no correction made and I was fine with that, but obviously you don't know what you're talking about. Go. Go away. (pg 29, lines 5-12)

In each of these three examples, parents express frustration over the lack of communication between their child's health care providers. When parents feel frustrated, they become more distressed. This added distress exacerbates suffering in

parental bereavement. Poor communication, whether it is insensitive or an overall lack thereof, cause parents additional suffering after the death of a child. This finding is consistent with findings from Contro, Larson, Scofield, and Sourkes' (2002) study which examined family members' perspectives on palliative care. Contro *et al.* (2002) found that family members experienced much distress after the death of a child upon recall of events involving poor communication that occurred during a child's premature, cardiac, or oncologic illness.

Insufficient information. Insufficient information is a second common hallmark of distressing care encounters reported by parents. Insufficient information received during a child's illness becomes a source of distress in parental bereavement. After a child's death, parents recall care encounters in which health care providers failed to provide them with sufficient information that would help them make informed choices and better prepare them for their child's death to the extent possible. Upon recall of these care encounters, bereaved parents become distressed. Parents provide several examples.

A few parents describe the failure of health care providers to provide complete and unbiased information about their child's prognosis. Joan shares her experience of being uninformed about the reality of Joshua's prognosis which left her feeling unprepared for his death. Joan explains:

The doctors would round and they would say his prognosis was excellent...they said, "He's gonna live way passed 18. He's gonna be fine. He's gonna be fine. He's gonna be fine"...I think maybe I could have been prepared better...there was an 'everything is very rosy kind of picture'...he

had an 85% chance of complete remission with first line treatment and then when he had a bone marrow transplant, he had a 65% chance of remission. And if you are just 1 person, you are not a statistic...85% , but how about the 15%? I mean he was only one. He was only one. So you can't be 85% living and 15% dead, so I think those statistics are really screwed up... The doctors would round and then tell us he was going to be fine. He's going to be fine. But he wasn't *fine* [emphasis added]! Even after he relapsed, I remember the doctor couldn't believe that he relapsed. [The doctor said,] 'He couldn't have relapsed'. Well, *he did* [emphasis added]!...We were totally unprepared for him dying. Maybe I was in denial. Maybe I was told but I couldn't hear it. I don't think so, but maybe. (pg 2, lines 10-13; pg 79, lines 10-23; pg 80, lines 1-6)

From Joan's example, it is clear that a significant breakdown in information sharing, a core concept of patient- and family-centered care, occurred.

When health care providers do not include families in discussions of their child's care, information is withheld leaving parents to feel ostracized from matters concerning their own child. Further, when health care providers selectively share information about a child's prognosis, focusing solely on the likelihood of survival, parents feel unprepared for even the possibility that their child might die. Care encounters involving insufficient information such as that described above remain a great source of distress for Joan 15 years after Joshua's death.

Peter encountered a similar encounter. Health care providers fell short in fully disclosing the reality of Robert's DIPG prognosis and, as a result, Peter lacked the necessary information to make informed decisions that would optimize Robert's quality of life. This causes Peter much distress to this day. Peter explains:

One day I cornered the doctor's associate and I say, 'Look, here it is February. I've been waiting for this kid to...be able to do some fun stuff'. That year we had a ton of snow. He hadn't been outside to go out on a sled or nothing. [I

said], ‘When am I going to be able to do this?’. And they just looked at each other. My wife caught it. I didn’t catch it. But somebody should have told me that there’s x% kids don’t get better after radiation, alright? Instead of making me...not making me, but I was hoping, ‘Ok, let’s go have this done for a week or two and then...we can go to Disney’...I wasn’t informed of it because, in their effort of being compassionate, nobody comes right out and tells you, ‘Ah, guess what? You are not in that percentage’. And when I nailed the doctor down he goes, ‘What do you want me to do give you percentages?’ I said, ‘No, because if it’s only 1% to me its 100% ‘cause I’m in the 100%’. I’m in there, but a little information would have been good...in general I understand not overloading you with information especially when the reality of it is when I say... 6 to 9 months you pretty much don’t hear anything for the time that I’m talking. I get that, but I also feel annoyed at the spoon feeding of information. Not that I want to hear the terrible, but you know what, give me a *hint* [emphasis added] so I can make an informed decision! (pg 10, lines 9-17, 19-23; pg 11, lines 1-2; pg 14, lines 11-16)

Once again, a breakdown of information sharing about prognosis occurred and causes distress upon recall.

When health care providers fail to provide sufficient information about potential treatment intervention consequences, parents experience distress. Peter wanted honest information not only about likely positive outcomes of treatment interventions but also about potential harmful consequences. From the time of diagnosis, Peter wanted to know if Robert would return back to baseline with resolution of all treatment side effects. Peter asked the physician, “Am I going to see my son again?” (pg 32, line 17). The physician replied in a manner that gave Peter false hope by saying, “Yeah, it will take a while but yeah you’ll see him” (pg 32, lines 17-18). Peter says, “that never came to fruition” (pg 32, line 10). Peter wanted to know not only what treatment options were possible but also what the likelihood was that they would or would not work. For example, Peter wanted to know what to

expect when Robert was extubated. When Peter inquired what might happen after extubation, the physician replied, ‘Well, I’ve never seen anybody not respond to being extubated. They usually breathe on their own” (pg 29, lines 14-16). Peter’s response was:

Robert hasn’t been textbook yet. What makes you think he’s going to be textbook now?...All these things that you set up, he hasn’t followed any of them. What makes you think that now it’s going to be and not to be a jerk but there is a first time for everything. (pg 29, lines 16-19)

Peter adds:

I understand...she was dealing in a compassionate way as possible. She’s a human being...the misinformation, whether they were trying to make it more palatable for me or not. I don’t know. Who knows?...a little information would have been nice. (pg 29, lines 20-21; pg 30, lines 17-18; pg 45, line 11)

When health care providers fail to provide sufficient information about signs and symptoms that are common at end-of- life, parents experience distress. Peter shares two examples. In the first example, Peter recalls the unclear explanation he received about end-of-life fatigue:

We were told that...he should be very tired. He was sleeping 23 hours a day. So I said, ‘Look, your idea of fatigue is like saying the ocean is deep’... so then they changed to term to ‘somniaolence’...ah, that’s great too...I never heard of ‘somniaolence’ before. (pg 10, lines 4-6; pg 13, line 12)

In the next example, Peter recalls the lack of information he received about respiratory distress being a common sign near the end-of-life. As a result, when Robert started to have trouble breathing in the swimming pool during the family’s overnight stay at a local resort, Peter had no idea that end-of-life was quickly approaching (pg 28, lines 7-12). Peter says:

No one told me that respiratory distress was the sign for end of life...I don't know what that information would have done at that time, but I learned a whole lot more after he was dead than before he was dead, which, 'Oh great, good time to know that!' And that's what I put up with, *a big stupid jerk* [emphasis added]! (pg 28, lines 12-16)

Open, honest, and simple explanations of fatigue severity and respiratory distress may have helped Peter to better understand and be better prepared for what was likely to occur near end-of-life. If health care providers had more clearly explained common end of life signs and symptoms, perhaps additional distress in parental bereavement could have been minimized.

When health care providers fail to provide sufficient information about hospice care, parents experience distress. For example, the manner in which hospice care was explained left Peter with the understanding that Robert would no longer be cared for.

Peter explains:

We had hospice come in ...hospice doesn't know what they're talking about...they meant well, but [they said,] 'We are going to be the liaison between you and the doctors. No more doctors'. What do you *mean* [emphasis added] there's no more doctors?! [They said,] 'Yeah, no more doctors'...They said, 'there's no more doctor visits. There's no calls to 911. If there is any need, you call us and we'll take care of it. Yes or No? Sign it, yes or no'. We were instructed to sign. (pg 9, lines 14-16, 18-22; pg 10, line 1)

This was extremely distressing for Peter at the time and remains so today, one and one-half years after Robert's death.

When health care providers fail to provide information about the option of tumor tissue donation in advance of a child's possible death, parents experience distress. Of all information sharing deficiencies, Peter is most distressed about the

complete lack of information he received about possible tumor tissue donation (pg 33, lines 18-20, 22-23; pg 34, lines 1-11). Peter says:

They need to be a little more upfront with the tumor donation from the beginning so maybe people like my wife could absorb it and digest it so by the time end of life comes [we can make an informed decision]...It was never mentioned. I found out about it on the website...Saying to parents whose kid is sick and they're hoping that things are going to go their way, 'Oh, by the way, can we have his brain?' is a difficult conversation to have...Even at the end when I started to bring it up, the...specialist who has been involved in DIPG since the late '70s...wasn't gun-ho about getting a sample. Now, would it help me if next year researchers said, 'Well, we found something from this sample'? Maybe not...maybe. (pg 33, lines 18-20, 22; pg 34, lines 4-11, 14)

By failing to discuss the possibility of tumor tissue donation with Peter, health care providers took away one opportunity for Peter to find meaning in Robert's death. As a result, Peter experiences much distress over this.

Exclusion from child's care. When parents recall care encounters during which health care providers excluded them from their child's care, parent's distress is exacerbated. Kelly becomes very distressed when recalling care encounters in which she felt physicians and nurses didn't listen to what she thought was best for Sam (pg 10, lines 19-23; pg 11, lines 1-15, 18, 20-23; pg 12, lines 1-3; pg 12, lines 17-19; pg 15 line 8; pg 128, lines 2-8). Kelly recalls a specific encounter that occurred on a weekend. Sam was complaining of a stomach-ache. Kelly knew it was most likely because he was constipated and in need of a stool softener suppository. Rather than listening to Kelly, the weekend resident physician insisted the symptoms were indicative of a shunt malfunction and ordered an x-ray. Although Kelly was very

concerned that the x-ray would be bothersome for Sam to endure, she was left with no choice but to consent because the resident was insistent. As it turned out, the x-ray confirmed constipation and a suppository was eventually ordered. Recalling this encounter is distressing for Kelly because it exacerbates feelings of frustration and anger. Kelly adamantly states, “I hate the weekend doctors. Can’t stand them. Can’t stand them with a passion...and that’s why most weekends I wouldn’t let any of the residents come in and some nurses” (pg 10, lines 16-17; pg 11, lines 21-22). The fact that Kelly’s knowledge of Sam and wanting what was best for him was not validated by the team is a source of Kelly’s present distress.

This encounter illustrates a breakdown in two patient- and family-centered care core concepts: respect and dignity, and participation. The core concept of respect and dignity was not upheld because health care providers discounted Kelly’s knowledge of her child. The core concept of participation also was not upheld. The Institute of Patient-and Family-Centered Care defines participation as follows: “Patients and families are encouraged and supported in participating in care and decision-making at the level they choose” (retrieved from <http://www.ipfcc.org/faq.html>, 8/7/13). Kelly was not encouraged nor supported to participate in decision-making; rather, health care providers assumed that responsibility completely.

Joan provides another example of the distress bereaved parents can experience as a result of having been excluded from their child’s care. Fifteen years into parental bereavement, the feeling of being excluded is still very fresh for Joan. Joan explains:

At that time you couldn't look at anybody's chart...but, I'd go take his chart. They threatened to call security on me. They said they were going to throw me out of the hospital if I took his chart again or if I looked at his chart. *I wanted to see his chart* [emphasis added]!! *I want to see what you're seeing* [emphasis added]!! You don't talk in front of the child and parents and *I wanted to know what was going on* [emphasis added]! I don't think I was well informed during the whole process...I felt like everybody was against me for some reason. I remember that feeling quite clearly in the hospital. It was like them against me. (pg 80, lines 6-16)

When health care providers exclude parents from care-related discussions and withhold information, parents feel ostracized and powerless to help their own child.

From Joan and Kelly's examples, it is clear that a significant breakdown in patient- and family-centered care occurred. Excluding parents from the planning and delivery of their child's care and withholding information violates the core concepts of respect and dignity, participation, and information sharing. This is not only distressing for parents at the time of occurrence but remains so throughout parental bereavement. This finding supports findings from Contro *et al.*'s (2002) study which indicate that when families felt that they were dismissed from their child's care or perceived hospital staff disregarded their judgment about their child's care, they experienced considerable distress specifically related to these events six months to 2.5 years after the child's death. Contro *et al.* (2002) state, "a single event could cause parents profound and lasting emotional distress" (p.15). The same can certainly be said of Kelly and Joan's parental bereavement experience.

Differences in goals. Differences between health care provider and parent goals also become a source of distress in parental bereavement. After a child's death, bereaved parents recall care encounters in which their goals were different than those of their child's health care providers. Upon recall of such encounters, bereaved parents become distressed.

Kelly provides an example of an encounter in which the pediatric nutritionist's goals were different than her own goals (pg 10, lines 1-5; pg 125, lines 4, 14-17). Following a seizure, Sam became comatose five days prior to his death. The pediatric nutritionist's priority goal at this time was to do a comprehensive nutrition assessment that included interviewing Kelly about Sam's nutrition. This was very distressing for Kelly because, for her, spending quality time alone with Sam was of greatest importance. Kelly explains:

Coming in wanting to know about his nutrition?...*Get out* [emphasis added]!. What is the *matter* [emphasis added] with you?! I don't want to know anything about nutrition. My son is in a coma. We're probably not gonna [*sic*] get to talk to him again and *you're worried about nutrition* [emphasis added]?! *Get out* [emphasis added]! (pg. 10, lines 1-5)

It is evident that recollection of this encounter remains very distressing for Kelly more than a year after Sam's death. Recollection exacerbates feelings of frustration, anger, and powerlessness. Kelly states, "*Stupid* [emphasis added] people that came in...*stupid* [emphasis added] people...the nutritionist, *get out* [emphasis added]!" (pg 9, lines 18-19).

Kelly provides a second example. Kelly expresses her distress over priority goal differences with the pediatric pain management service. Kelly recalls a specific care encounter in which the pain management physician wanted to decrease the dose of Sam's pain medication and she wanted to maintain the current dose. Fearing that Sam would be unable to communicate any increase in pain intensity due to his comatose state, Kelly wanted to maintain the current dose (pg 125, lines 17-18, 20-22; pg 126, lines 1-2, 4-9, 11, 13-14, 16, 18-20). Kelly explains what this care encounter was like for her:

There was another guy who thought he was like bee's knees. I don't what to hear that you are the head of whatever...He came in and said he was the head of this, the head of that...and I was like, 'yeah, and?' And I know I was totally rude. I know I was. And basically, just like the nutritionist, I asked him to leave. I was just basically like, I don't care who you are. He wanted to... decrease Sam's...pain medication...we used to say, 'well how do we know if he is going to be distressed and he's not showing us any signs? *You are not touching him* [emphasis added]! *You are not touching him* [emphasis added]!' (pg 125, lines 17-18; pg 126, lines 1-2, 4-8, 13-14, 16)

The details of this care encounter remain clear in Kelly's memory more than one year after Sam's death. Feelings of frustration, anger, and powerlessness are just as fresh now as they were then.

Peter also tells of a care encounter in which a health care provider's goal differed from his. While the physicians wanted to continue with Robert's current treatment, Peter was hesitant to do so when it became apparent that the treatment was not having any favorable effect (pg 15, lines 2-19; pg 33, lines 14-18). Peter explains:

The doctor... [initially] said,... 'I'm not beholdng to the research. My first and foremost responsibility is to Robert. So if we don't see anything happening, I

may stop and we may look for other avenues to take and usually I stop before the parents stop'. Well, it was a 20 week trial and we were 16 weeks in and nothing but things getting worse. When I questioned, it was, 'Oh, be patient'. No, I'm not being patient. Its 16 weeks in. I'm not seeing anything, ok...I said, 'Look, the investor in me says high risk, high reward so if I'm going to pump down my money on your imagination I want to get two and three fold in five weeks. If I want slow and steady, I'll by Con Edison. Ok?' [The doctor said,] 'Well, you also got to be conservative too'. Be *conservative* [emphasis added]? We're giving an 11 year old kid chemo and nothing's happening, how conservative do you want to be? Of course, they have no answer...And yeah you're hoping and my wife too is. We got to do something. Yeah, we got to do something but all the facts that I looked up show me no one has survived this yet. Yes, I want my son to be a professional golfer but at what cost? (pg 15, lines 2-19)

When health care providers' goals differ from parents' goals, parents experience distress. Distress occurs not only at the time of the encounter but also throughout parental bereavement. When parents recall care encounters in which their goals for their child's care differed from health care providers' goals, parents acutely experience an increase in frustration, anger, and powerlessness. This additional distress exacerbates suffering in parental bereavement. In addition to common distressing care encounters described above, there are isolated reports of other distressing care encounters that involve a lack of continuity, inflexible hospital policy, treatment delays, and abandonment.

Inflexible hospital policy. Peter remains very distressed about the inflexible hospital policy that prohibited Robert from trick-or-treating on the Halloween before his death (pg 25, lines 14-23; pg 26, lines 1-10; pg 45, lines 15-17). Peter explains:

Halloween at [Children's Hospital] stinks. Now, I understand it, but I don't understand it. You have kids with cancer. Some are going to come out of it. I don't know what the percentages are, but some are. It was his last Halloween

and he couldn't go trick-or-treating. He wanted to go home in the worst way. We went around the hospital, which nobody had anything. [Robert said,] 'I don't care! I'll even go trick-or-treating in [town]. I wanna go trick or treating. I want to go [around] the hospital [and] take the candy'. I understand they don't want you going into each kid's room. No, no, no, no candy. Sugar. Cancer gets the first call for sugar and that increases the size of the tumor. Ok, I gotcha. I've been on this earth a little longer than a day. I know that this [sandwich] is a carbohydrate and this creates sugar. There's no sugar in it. This has sugar in it and a candy bar has sugar in it and everything has sugar in it, so if the kid has candy on Halloween and it makes his day and it's not his last Halloween, what is the problem? What about the kid that it is his last Halloween?...They are a little ridiculous on some things....it's just odd. It's like that genius in the room who's not so smart. He's really, really smart in the books like, 'Oh my goodness, in this subject he is fantastic', but he can't cross the street without getting into trouble....you're kidding me right?! (pg 25, lines 15-23; pg 26, lines 1-10)

It is most unfortunate that hospital policy not only prevented Robert from Halloween trick-or-treating, a typically joyful childhood activity that would have greatly improved the quality of the last five months of his life, but also continues to bring Peter significant distress after Robert's death.

Lack of continuity. A lack of continuity can be distressing for parents not only during a child's hospitalization but also after a child's death. Having primarily been cared for in the outpatient pediatric clinic, Cindy's admission to the inpatient pediatric unit was very frightening for Doris (pg 38, lines 10-13). Doris explains, "that was probably the scariest day...I wasn't familiar with how the floor worked... so that was...one of my worse days because I was a nervous wreck" (pg 38, lines 12-13). Over two years later, Doris clearly remembers the fear that she felt that day as a result of receiving care from different caregivers in a different environment. In addition, a lack of continuity in hospital services contributes to on-going parental dissatisfaction.

Kelly expresses dissatisfaction over downsized hospital services that occurred on weekends, including the closed cafeteria (pg 13, line 1), the closed activity room (pg 12, lines 21-22), and the absence of child-life specialists (pg 14, line 10). Almost two years after Sam's death, Kelly expresses continued dissatisfaction especially when visiting Sam's friends in the hospital because she knows how difficult it was for Sam when he was hospitalized (pg 12, lines 18-19, 21).

Treatment delays. Treatment delays can contribute to parental distress. Doris still experiences distress when recalling the delay that occurred when Cindy was transferred from the emergency department and to the inpatient pediatric unit. Doris explains:

That day was awful... the reason it was so awful...was because of some of the restrictions of the building and the time it takes to get from A to B, because...you're going on the heme-onc floor so you have to take patient A out of this room just to move patient B...it's hard because in your mind as a parent...she's the only child on earth that is dying of a brain tumor so could you get on it? ...You need to do everything for her. (pg 40, lines 11-15, 18-20; pg 41, line 2)

Abandonment. Another source of distress is abandonment by health care providers who were once so supportive during a child's illness. Kelly becomes visibly distressed when talking about Sam's school nurse, who was once a significant support during Sam's illness but now is no longer present (pg 33, lines 15-23; pg 49, line 22; pg 50, line 1-4; pg 79, lines 20-22; pg 80, lines 12-14, 16, 18, 22-23; pg 81, lines 1-2, 5-6, 8-10, 12-13, 15, 17; pg 84, lines 5-12; pg 123, lines 13-14, 16-17). Kelly explains:

The school nurse who was extremely close since the day I told her Sam had a brain tumor...she never let us go...I mean, if she didn't hear from me two or three times a day, she would come around to the house. I mean that's...how close she was and now...I hardly hear from her at all...that just broke my heart...She'd call me three or four times a day when I was at the hospital. She knew the day Sam was going to...pass away. She knew the *hour* [emphasis added]...how many hours he had left. She was *there* [emphasis added]. She wouldn't let me go. Wouldn't let the family go...I haven't got her anymore...*I let you in* [emphasis added]! I let you know the most personal stuff in my life...I mean there wasn't a day that she wasn't with us...I didn't even classify her as a nurse, ever. She was a *friend* [emphasis added]. *How could you* [emphasis added]? It was too personal. It was too personal. I guess can nurses turn off like that? I can only assume...I will be hesitant next time before I let someone in. (pg 33, lines 15-20; pg 80, lines 18, 22-23; pg 81, lines 1-2, 5, 9-10, 17; pg 83, lines 16-17; pg 123, lines 13-14, 16-17)

It is very hard when the support of the health care team that once was present, is now gone. Sara explains:

On top of the fact that we lost Adam, we lost all that medical support that we had had and the way of life that we had had for a long time...it's like, in the middle of the night you leave your home. You just left...and it was all gone...that was hard and then to go back home and try to start. It's like you're trying to start all over again. It's not the same as it was...their job is to care for sick kids and we didn't have a sick child anymore. So, it's not like we thought they should be following us around through life or anything like that. It just surprised us that there was such an abrupt break, a clean break like that and then there was nothing... they were some of the most important people in our lives for two years and then they're just *gone* [emphasis added]! (pg 23, lines 4-6, 10-14; pg. 103, lines 3-8)

Sara and Kelly's marked distress as a result of feeling abandoned by their children's health care providers is not unique. The literature is clear that the loss of supportive connections with their child's caregivers is a source of additional distress for parents after a child's death (D'Agostino *et al.*, 2008; Contro *et al.*, 2002; Darbyshire *et al.*, 2012; Heller & Solomon, 2005).

Parents' health care providers. A few bereaved parents describe behaviors of their own health care providers that have been a source of distress since their child's death. Kelly offers two examples. First, Kelly tells the following story of her visit to see a therapist following Sam's death: "I went to see a therapist...and I liked her very much...first session was great...second session [she says,] 'Who are you talking about?' ...*Oh* [emphasis added]!...*you didn't write anything down* [emphasis added]!...so, no, it did not work out" (pg 22, lines 20-22; pg 23, line 6). While a seemingly simple question on the part of the therapist asking Kelly who she was talking about may at first glance appear inconsequential, be not mistaken; it actually had serious, potentially detrimental repercussions. What is so unfortunate is that Kelly summoned the courage to seek out help in coping with Sam's death; however, the therapist's inattentiveness in remembering that Kelly was a bereaved parent essentially cut off all support for Kelly. Kelly's perception of therapy was so understandably negative as a result and it took a very long time before she could once again consider trying to find support by attending a bereavement camp. As a second example, Kelly talks about her visits to her medical doctor. Although her medical doctor listens to her when performing a routine physical exam (135, line 5-6), Kelly feels she cannot discuss in any great depth how she is coping with Sam's loss because the visits are so short (pg 135, lines 10-16).

Peter tells the story of how his wife's health care team failed to recognize his lived experience of parental bereavement and his lived experience of being his wife's

caregiver. Trisha experienced cognitive side effects from the multitude of medications prescribed for a serious illness. Peter was very concerned not only for Trisha's well-being but also the financial cost of needless medications (pg 45, lines 21-23; pg 46, lines 1-4). He raised his concerns to Trisha's doctor. The doctor refused to talk to anyone but Trisha because she was still coherent. However, Peter is Trisha's primary caregiver. Understandably, Peter was frustrated and angered by this. When Peter voiced his frustration, the health care team concluded that he was an angry man and refused to talk to him. Peter describes what this situation was like for him:

My wife was on a page and a half of medication. So, we don't know which one to change but I'm looking at her and here is this really sharp, intelligent woman. She is detailed to the nines and she's looking at me like she's lost. [My wife says to me,] 'Well, why don't you talk to them?' And I say [to the doctor,] 'Why don't you talk to me'. [The doctor says to me,] 'I don't have to talk to you'. [I say to the doctor] 'You don't? When it comes time to get paid, who are you going to come see?... You know something, I think you should go back to your school and get your money back and give it back to your father. You wasted your father's money. I'm telling you right now. Just because...that this is the Cancer Institute and...just because you get an A during the semester, doesn't mean you aced the class. You guys stink. You stink! This is blatantly dropping the ball. Extremely unprofessional. Extremely unprofessional!' So, I lost [it]. I blew my top....they didn't call security which was good, but I let them know I wasn't happy.... the doctor, the resident on call, the senior doctor...not two words to me. Alright, but the nurse made a point to tell my wife that...I have anger issues. [The nurse said] 'Your husband is passive aggressive'. I says [*sic*], 'Oh, so she's a psychiatrist now?... she better get a dictionary too 'cause that's not what passive aggressive is'. (pg 40, lines 7-13, 15, 17-18, 20-23; pg 41, lines 2, 4-6, 8-9, 11-12, 16-18)

If the health care team had considered Peter's lived experience perhaps they could have handled this situation differently so as not to add to Peter's distress.

In summary, health care providers' behaviors and care processes cause bereaved parents additional distress. As a result, suffering after a child's death is intensified. This finding is striking and adds to a paucity of literature concerning how care influences parents' lived experience of parental bereavement. Nursing, medicine, and other health professions can and must do better. Health care professionals must be better educated in this regard.

Chapter VII

PARENTING RELATIONSHIP CONTINUES IN THE PRESENCE OF THE CHILD'S ABSENCE

To experience parental bereavement is to continue the parenting relationship in the presence of the child's absence. This is an essential aspect of the parental bereavement experience. A discussion of the two underlying subthemes follows.

Presence of the child's absence

After the death of a child, parents live with the presence of their child's absence. The child's absence is omnipresent. To live with the child's omnipresent absence is to live with something that is always missing. Peter explains:

You ever go on a trip, gone away for the weekend? You're going to work this morning and you get that feeling that something's missing? Well, something is always missing...my wife and my family will never be the same again. (pg 21, lines 4-7)

It is unimaginable that life continues on in child's absence. Joan says, "I couldn't believe the sun rose every morning without my son being on this earth" (pg 52, lines 13-14). Sometimes a parent can momentarily forget that the child has died and is absent. Doris explains what it was like for her to momentarily forget:

I would be doing something and I would think 'oh gosh, I shoulda heard from Cindy right now', or 'I gotta get Cindy picked up', or 'I can't stay for this because there were things that [we have to do]. There were split seconds right after she died where I really did almost forget and for a minute or for a second...I believe in my head I really thought that she was still alive. (pg 111, lines 9-14)

Doris experienced such a moment when she saw a picture of a girl who physically resembled Cindy. Doris explains, “I looked at it and, for a brief second, it was like such a great sense of relief. You know, ‘Oh, look there she is!’ Of course,...I’m smart enough to clearly know that wasn’t it” (pg 111, lines 16-18).

Everything in a parent’s life is marked by the child’s absence. Doris explains:

Every single thing is still tainted or clouded...by her loss, by her not being here...*every single thing* [emphasis added]!...Every single thing that I do now is colored by her loss. It doesn’t matter whether I’m brushing my teeth and I’m brushing my teeth alone because she’s not shoving me out of the way in the bathroom sink, or I see a girl who looks like her, or a friend complains about their child misbehaving. I see everything through her loss. (pg 58, lines 19-23; pg 109, lines 11-12, 14)

Doris adds, “I don’t know how you erase that. I guess our children are our children and maybe I don’t want to erase it...maybe I don’t want to” (pg 109, lines 11-12, 14-16). The underlying meaning being that as difficult as it is to live in the presence of Cindy’s absence, Doris does not want to entirely obliterate her awareness of Cindy’s absence. For if Doris’ awareness of Cindy’s absence lessens, then so too does her connection to Cindy. Because of this, living in the presence of the child’s absence has importance.

There is no escaping the presence of the child’s absence. Kelly explains how Sam’s absence was felt so acutely even on a respite vacation:

Even [being on vacation] reminded [my husband and son] of when Sam was there...Did the trip help? *No* [emphasis added]!...‘cause it didn’t change anything. It didn’t change anything... It didn’t change anything. Was it worth it? No. It’s just a very difficult situation, that’s all. A very difficult situation. (pg 61, lines 12-13, 15, 17-19)

The child's absence forces change in a parent's everyday life, such as the number of seats and place settings around the dinner table, the child's bedroom configuration, holiday celebrations, and the size of family car that is needed. Joan explains, "I had to do everything different when he died, everything. Every holiday...everybody had to change seats at the kitchen table 'cause...I couldn't have everybody sitting in the same seat anymore because there was always that empty seat" (pg 31, lines 14-19). Kelly adds, "things are changing. Things don't include him anymore" (pg 99, line 2).

The child's absence leaves a void that can never be filled. Doris has found this to be true in her experience. Doris explains that Cindy can never be replaced. As much as Doris enjoys being actively involved in the life of Cindy's best friend, Mary, it hurts because Mary is not Cindy (pg 97, lines 21-22; pg 98, line 1). Doris describes a time when she hosted a mini eighth grade dance for Mary and encountered this hollow void:

I felt so good about doing it for Mary and I loved doing it and then when they left, it just wasn't enough. It wasn't Cindy. And no matter how happy, how good I felt, and I knew Mary and I knew I had done something positive for Mary and the void, I tried hard, but it just didn't get filled. So, I think that's a bit of a lesson for me too. I can't expect Mary to [fill the void]. I got my feelings hurt a couple of times....Mary has said, 'I just wish I could be with my mom' and in those moments I have found...it's like you just hit the wall and you're like '*Crap* [emphasis added]! You can pretend all you want but she's still not *your daughter* [emphasis added]! You can try to make yourself believe that but, in the end, she has mom...I love to see how much she loves her mom, and then there's the, 'Oh woe is me. I want Cindy to love me too like that'. (pg 97, lines 22-23; pg 98, lines 1-5, 10-17)

Emma also shares that her daughter's absence leaves a void that can never be filled. Soon after Dorothy's death, Emma wanted to adopt a young girl from an orphanage; however, her husband was only agreeable to adopting an infant out of concerns that Emma was trying to replace Dorothy. This was not the case. Emma explains:

There was this little girl out in the hallway and she was the exact age as my daughter...I started talking to her and I fell in love with her...I told my husband I would like to adopt. He said that would be fine...I said I want to adopt that little girl...he said, 'If we adopt, it has to be an infant'. I said, 'I don't want an infant. I want that little girl'....I think about her and pray for her all the time. I hope she had a good life, that somebody good [adopted her]...but...he said, 'No, you'll just be living Dorothy's life through her'...I said, 'No, 'I know she is a separate person'. She was just so sweet to talk to...I can't remember [her name], it's been so long, but I can see her face. (pg 42, lines 20-23; pg 43, lines 1-4, 6-8, 12)

Emma knew this child would never and could never replace Dorothy.

The child's absence makes previous enjoyable activities very difficult. Doris is no longer comfortable going to church and explains, "to go to that space, that actual place, where those families are still there and their kids are doing what they should do. I guess I feel envious or jealous" (pg 62, lines 19-22). . Kelly adds:

Special events that we used to go to...I mean everything, the first anniversary of everything that Sam wasn't going to be with us...we would be quiet. We would be quiet because we knew that it wasn't right...Sam should be with us. (pg 54, lines 12-16)

Activities that parents once enjoyed doing with their child cease entirely. Peter fondly recalls the fun he had with Robert when they would play math games and explains, "all of that has gone away" (pg 3, line 4).

Parents describe numerous situations which bring a heightened sense of their child's absence which, in turn, trigger intense grief. The child's absence is, in and of itself, a grief trigger. Therefore, it is no surprise that the same situations which trigger a heightened sense of the child's absence also trigger grief. Situations that trigger a heightened sense of the child's absence and subsequent grief include the following: a) remembering something the child said or did; b) doing errands that the child enjoyed doing; c) looking at pictures and watching videos of the child; d) looking at pictures taken before the child was born; e) returning to the hospital; f) going on family vacations; g) confronting developmental milestones that the child will never do, such as riding the same school bus for the first time with older siblings, entering high school, going to prom, going to homecoming, receiving confirmation, getting married, and having children; h) beginning a new school year; i) celebrating holidays and birthdays; j) attending church; k) seeing another child who looks like the child; l) seeing the child's friends; m) seeing the child's friends making new friends; and n) seeing their own friends with their own children and grandchildren. Parents share a few examples to illustrate what it is like for them to live with their child's absence. As Kelly prepares for her children to leave for summer camp, Sam's absence is present. Kelly explains: "I keep thinking about Sam because he should be going to camp and he's not going to camp...I'm not packing his suitcase...I'm not taking his things...the kids are going to camp without him" (pg 121, lines 12-16).

For Peter, Robert's absence is present as he watches his friends mature. Peter shares "to see [Robert's friends] grow... is... understandable, but it's very difficult...it is hard to see his friends and to see how much they've matured or grown or gotten better at hitting baseballs or how intelligent they are now" (pg 5, lines 16-17, 19-22; pg 6, lines 5-7). Doris describes what it was like for her to confront the presence of Cindy's absence in the moment when she first learned that Cindy's best friend, Mary, had made a new best friend:

I just literally thought somebody had punched me in the stomach....It just took my breath away to think life is moving on and Mary is making friends...and for just a second I felt like I was in a wind tunnel and somebody just pulled all the air out of my stomach! (pg 68, lines 12-13; pg 69, lines 2-3, 5-7)

Doris's voice conveyed the abruptness and intensity of this moment. Doris describes a similar sensation when she saw a picture of a child who resembled Cindy and explains:

I looked at it and I think all the wind sucked out of my lungs in one fell swoop because just for one second I saw Cindy. The way she stood, the way her hair was in a ponytail, the way she was standing with her arm around Mary, the whole thing. (pg 110, lines 14-17)

Sara acutely sensed the presence of Adam's absence when she found a picture of her family of four taken before Adam was born. Sara explains what this was like for her:

It's almost as if, because Adam was our youngest, it's almost as if he never lived...which I know that is not true...we have a family picture and I noticed it after Adam had died. It just happened to be a picture that was out and it was before he was born...it was my husband and I and my two older ones and...it does seem so cruel sometimes because it's almost seems like did it really happen? *Did he really live* [emphasis added]? So that's probably the hardest part of this for me. When I think of how hard...it will be three years come this December,...it really does seem like a really long time without him...but then,

we're at two and one half years right now and it doesn't seem like a really long time either when you think about it...it's just a hard thing. (pg 79, lines 18-23; pg 80, lines 1-8)

Emma reflects on Dorothy's absence and considers what her life would have been if Dorothy was alive, saying:

I see my friends that have daughters and the daughters take care of them and they do things together...it still hurts, that's all I can say...I always think that if Dorothy had... lived,...she would have been...such a blessing. (pg 55, lines 18-21; pg 65, lines 12-15)

Situations like these trigger a heightened sense of the child's absence and as a result, a greater intensity of grief.

Of all the grief emotions parents describe in their parental bereavement experience, the child's absence most intensifies a parent's longing for the child. Parents miss their children deeply and long to be with them. Emma says, "I still, still miss her so much...I will always miss her" (pg 16, line 19; pg 80, line 13). All parents share similar sentiments. Doris says:

At night when things start to wind down and I think, I wish she was here...if I had a choice I would probably prefer to be in Heaven with Cindy, but I don't have a choice. That's not an option, so I will do what I [have to] do (pg 64, line 17; pg 70, lines 21-22; pg 71, line 1)

Parenting Relationship Continues

In spite of the child's physical absence, the parenting relationship continues indefinitely throughout the parent's lifetime. Simply stated, *parenting* means "to be or act as a mother or father" (retrieved from

http://www.oxforddictionaries.com/us/definition/american_english/parent?q=parentin

[g#parent_12](#)). The term *relationship* refers to the connections and bonds that a mother or father has with a child and includes certain qualities, such as feelings of closeness and emotional attachment (Lutz, Anderson, Pridham, Riesch, & Becker, 2009).

Emma offers evidence of the continuing parenting relationship that she maintains with her daughter, Dorothy, 41 years later when, she states, “I never stop thinking about her and loving her” (pg 55, lines 10-11). Sara also conveys the continued nature of the parenting relationship, explaining “Adam will always be my son, whether it is today, or five years from today, or 25 years from today” (pg 93, lines 4-5). Kelly echoes Emma and Sara’s feelings, stating “[Sam is] always there with me, always, always” (pg 99, line 14-15). The parenting relationship continues in spite of the child’s physical absence.

After a child’s death, the parenting relationship continues albeit in a different manner. This different nature of parenting is *parenting beyond the veil of death*. Sara explains, “parenting beyond the veil ...is a different kind of parenting...I just have to rest in the Lord that Adam is fine, but he is still my son. I am still his mother” (pg 43, lines 20-22). To give insight of what it was like for her to begin preparing to parent beyond the veil, Sara shares a spiritual experience that she had just prior to Adam’s death. Sara states:

I just remember surrendering him to God and not knowing whether he would grow up in our home on earth...I basically said,...‘Lord, if You want to take him’...I was basically just telling the Lord that that was ok... and that I wasn’t going to be angry. (pg 46, lines 3-4, 6, 14-15)

Sara describes another example of parenting beyond the veil in her journal: “Early this morning Adam’s soul left his earthly body for his heavenly home...while cradled in the arms of his mother and surrounded by loved, he breathed his last breath in this world and awoke in the next” (Sara, personal communication CaringBridge® journal entry, December 4, 2009, pg 47, lines 28-30). To this day, Sara continues to parent beyond the veil through meaningful activities done in Adam’s honor, such as participation on Children’s Hospital committees and DIPG community work. In her journal, Sara writes:

As parents we do all we can to care for our children--to make sure that they are fed, clothed, sheltered, and safe. We plan for academics and for life-enriching experiences. We dream about the future. But we don't usually think about memorializing our children in a meaningful way. (Sara, personal communication CaringBridge® journal entry, March 25, 2011, pg 5, line 31-34)

Like Sara, other parents actively participate in many different types of meaningful activities to varying degrees in honor of their children, such as volunteering at a homeless shelter, starting a non-for-profit organization with a mission of carrying out what their child most valued, advocating for children’s safety, being involved in the childhood cancer community to advance research and education, and continuing to live their own life. Emma explains, states, “To honor your child is to go on with living. That’s how I honor her” (pg 80, lines 8-10). In all of these ways, parents parent beyond the veil. Parenting beyond the veil of death continues the parenting relationship indefinitely.

As parents continue their parenting relationship they stay deeply connected to their children. There are many things that parents do to feel more connected to their children, including the following: a) feeling sad; b) participating in meaningful activities; c) speaking aloud to their child; d) writing letters to their child; e) talking to others about their child; f) displaying pictures of their child around the house; g) uploading their child's picture onto their cell phone; h) keeping their child's bedroom the same; i) assembling a shrine of their child's favorite things; j) keeping their child's dirty clothes safely stored in a Ziplock® bag that can be opened to smell their child's scent; k) keeping their child's medical supplies; l) visiting psychics; m) staying connected to their child's friends; n) getting a tattoo of their child's name; o) wearing their child's jewelry; p) writing and posting videos on their Facebook prayer page; q) lighting candles; r) attending events in their child's honor; s) arts and crafts; t) celebrating child's birthday; u) displaying child's cremated remains in an urn in the home; v) attending yearly memorial service; w) going to cemetery; x) hanging child's Christmas stocking full of written letters; y) keeping child's personal belongings; and z) remembering.

Not every parent finds all of these acts to be helpful in maintaining connections to their children. For example, while some parents have found psychics to be very helpful in strengthening their connection with their child, other parents have not. Joan has found psychics to be very helpful. Joan describes herself as a "psychic junky" (pg 10, line 23). Joan explains, "I want any connection I can get with my deceased son"

(pg 10, lines 20-21). Joan shares her experience of psychic readings and provides the following example:

I've gone to a few psychics and they've told me a few things that if they weren't legitimate they could [not] possibly know...We had just taken our older daughter to London. My husband and I,...my daughter and I were walking around [trying to find]...this little Peter Pan statue in Kensington Park...we walked around for hours and she's like, 'Mom, you're never going to find it. Forget it'. And so we went back to the hotel and the next time my husband took us out we found it – the statue. But that's not anything I'd ever come back and tell anybody, 'Oh, I went to London and we were looking for this Peter Pan statue'. So anyhow, I wanted to get tickets to John Edwards Crossing Over and I couldn't get tickets, and I couldn't get tickets and this woman called me...she said, 'Hi, I have two tickets to John Edwards for this Tuesday. Do you want them?' And I thought, 'Oh, she's just being cruel because she probably knows that I've been driving my husband crazy' but I want tickets to see him. And she wasn't being cruel. She really had two tickets that she couldn't use them. They were in her name. And to make a long story short, I took a friend and we went down to John Edwards, and my son definitely came to him. [John Edwards] said, 'I see something about Peter Pan, what is this? Was he young and he just had this vision he wouldn't grow up or something?' I had just come back from London. This had just happened with this Peter Pan statue the week before and I didn't come back and tell anybody. Even if you investigated me, he would never have found out that we had trouble finding Peter Pan, this stupid Peter Pan statue in Kensington Garden. He just knew so many things like that, so many small things that I had been through in the past year, John Edwards did, that I knew that my son was really there. And so, like I said, I just don't think that he's dead, he is no longer around. I just think he's not around in the fashion I'd like him to be in, in the human...body-mind-and- spirit sense. I think he is still around. (pg 66, lines 8-23; pg 67, lines 1-12)

In contrast, Doris has not found psychics to be of much help. Doris explains what her experience with a psychic was like. Doris states:

A part of me as a mom that really wanted to believe that...Cindy was really there. [The psychic] said a couple of things that I thought were pretty on target, but I'm still skeptical about that stuff [and] I had a hard time. There was a part of me that really just wanted to believe that Cindy was being herself, she was being on the stubborn side and she would talk to me when she

was good and ready, not just because I paid \$25 bucks to sit in a room for an hour and have [the psychic] conjure her up or something. (pg 112, lines 21-23; pg 113, lines 1-5)

Like Joan and Doris, Kelly has also tried reaching out to psychics. Kelly does so out of motherly concern for Sam, explaining:

That's why I'm trying to reach out to psychics...if only I could know that [Sam] was ok...I kind of feel scared for him because I'm thinking he's only a young kid. What's he doing up there on his own? You think of all these crazy things. (pg 46, lines 15-20)

Kelly hopes that psychics can help meet her strong, urgent need to communicate with Sam, explaining, "I went to a psychic. I've done everything just to talk to Sam" (pg 25, line 11). Due to Sam's comatose state near the end of life, Kelly was unable to talk with Sam before he died and explains:

I would have had conversation or something....I would have let him know it was ok. I would have actually said to him, 'Sam, if you need to leave'. If I knew he was there taking his last breath, I would have said 'Sam, it's ok. We'll be fine. We'll take care.' We didn't get that. We had the seizure... so it's not a case of...that I was going to say goodbye, but I would have given, I guess...is it awful to say I would have had the last word? Is that awful to say? As a mother? Because I didn't have a say in him leaving me...Maybe it is a control issue? And that's why I didn't want to let him go. I won't ever, ever. (pg 25, lines 20-23; 26, lines 1-5; 17-20, 22-23; pg 27, lines 1-2)

Remembering is something all parents do and find helpful. Thus, remembering is an essential aspect of the continued parenting relationship. Remembering helps parents feel connected to their children and strengthens the parental bond. No matter how much time passes, parents never forget their children.

In this study, all participating parents lovingly remember their children. As each parent remembered his or her child, I came to know Joshua, Adam, Sam, Cindy, Robert, and Dorothy. Joshua was sensitive, loving, affectionate, kind and wise beyond his years (pg 22, lines 11-14, 16-23; pg 23, lines 1-5, 8-12). Adam was a sweet boy who, with his sense of humor, brought lighthearted moments to his family and exhibited maturity during illness and grace in dying (pg 4, line 13-23; pg 5, lines 1-4, 22-23; pg 6, lines 1-10,12-16, 21-23; pg 7 lines 1-8, 14-19). Sam was very caring, had a great sense of humor, and excelled athletically (pg 2, lines 2-3; pg 5, line 13; pg 6, line 21; pg 33, lines 1-2; pg 54, lines 2-3pg 57, lines 19-21;pg 67, lines 13-14, 21; pg 67, lines 13-14). Cindy was a strong-minded, self-assured, independent, social, empathetic, kind, happy child, who thoroughly enjoyed music, theater, dance, and sports (pg 3, lines 18-23; pg 4, lines 1-18, 20-23; pg 5, lines 1-5,7-12; pg 6, lines 11-12; pg 7, lines 2-5, 8-9,14-22; pg 29, lines 5-6; pg 95, line 15; pg 96, line 15). Robert was academically gifted in math and always strove to do good (pg 1, lines 1-3, 10-13; pg 2, lines 15-18, 20-22; pg 3, lines 1-2; pg 6, lines 7-12,13-15; pg 12, lines 18-19; pg 31, lines 17-22). Dorothy was a very strong, wonderful little girl who loved to dye colorful Easter eggs (pg 11, lines 11, 19-20). The children became alive through their parents' stories of remembrance in a way so powerful that others, who never once met them, have the opportunity to come to know the children.

Remembering is powerful and has significant meaning. Remembering brings parents comfort. Remembering strengthens a parent's bond with his or her child in a

very real, tangible way. For bereaved parents, the power of remembering comes in being able to remember aloud in the presence of people who actively listen in a non-judgmental, compassionate manner and who understand their need to do so. In this way, others may be able to offer parents opportunities that might help them solidify bonds and facilitate continuation of the parenting relationship in the absence of the child's physical presence.

Bereaved parents must be supported in their efforts to stay connected to their child in whatever manner is most comfortable for them and whenever they so desire. When people thwart parents' attempts to stay connected, it can have negative consequences. For example, if someone refuses to listen to a parent who wants to talk about their child in order to feel more connected, the parent will feel more alone and isolated. Thus, suffering is intensified. If people prevent parents from keeping their child's personal belongings, parents' tangible connection to their child is broken and suffering intensified. Emma explains what it was like for her to experience this latter example. Emma tells a heart wrenching story of what it was like for her when others ripped away her connection to Dorothy in the early bereavement years. Her story is as follows:

Her *bedroom* [emphasis added]! When she came out of the hospital for the first time after 30 days, I was afraid that she wouldn't want to go back into the crib....We only had the one salary, so my husband's grandmother paid for a new bed for her...I had her room all picked up and everything...Of course,...she didn't come home...One day, my husband said that...somebody at work told him that the sooner he got rid of my daughter's things, the sooner that I would get over it. That's the biggest laugh in the world...If it was today, I would have stuck up for myself more but I was so in grief that I couldn't fight it...I sat on

the floor next to her bed and cried while he had some people come and take everything. *Everything* [emphasis added]! And I tried...I hid a couple things...I hid them in the closet in there, but it was like everything went. It went to good places. It went where...it was needed, but it should have been my choice...that was *so wrong* [emphasis added]! And that would never make me [get over it], you don't *get* [emphasis added] over it! They didn't understand. So, I think her things went to four different places...After everything was gone,...I asked my son was there anything [he] wanted...I thought... it's too late...he wanted this doll that was a soft, stuffed doll and it...talked...He and Dorothy would get on his bed and he would play it and...it would say, 'Are you ticklish? I am', and it would laugh. And he would tickle her and they would laugh. That was what he wanted....it had gone up to [the hospital] in the pediatrics [unit], so we called. The nurses up there said that they hadn't put that out on the floor. They kept it in the office because they really liked it. And they said come up and get it and *we did* [emphasis added]! And my son kept that. He kept that on his shelf in his bedroom until he got married!...I still have it in the other room. It was...special. And then...most of her clothes and her...bicycle and her table and chairs...my brother got a truck and took them up to the orphanage.... I told my husband [that] I wanted to go and see...where her things were...I just wanted to do that. So he called and the nun said bring me up and he did do that and we walked all through. (pg 40, lines 13-17, 23; pg 41, lines 1-10, 14-16, 18-23; pg 42, lines 1-4, 6-7, 9-12, 16-19)

Stealing the most tangible things that connected Emma to Dorothy was and still is anguishing. The last pieces of Dorothy's life were slipping from existence before Emma's eyes.

Because of people's ignorance about the parental bereavement experience, there was nothing Emma could do to stop this. Yet, in spite of deep grief feelings, she summoned the strength to salvage what she could. This doll is the last tangible piece of Dorothy's life and remains a powerful connection between them 41 years later. In a story Emma shared with me about her parental bereavement experience, she writes:

My husband listened to someone at work who told him the best thing to do, was to get rid of all her things. So I would "get over" my grief faster. This person had never lost a child and had no idea of the best thing to do. We

bereaved mothers know that when and if our child's things are put aside, it should be our call. To this day, I still feel sometimes as though the pain is still fresh. I do not have to see my daughter's things to make me sad. Her memory is inside of me and always will be. The day they came to clean out her bedroom was shortly after she had passed away. I sat on the floor beside her bed and cried the whole time. When I had a few seconds, when I thought no one was watching, I hid a few things in her closet. By having them taken away so soon, most of her things, just made it that much tougher to deal with her death. Now I am angry that I did not have the strength to stand up and say NO! Don't ever let anyone make this decision for you. There is no right or wrong way to do it. It should be our choice to do what feels right to us and when the time is right. (Emma's story, lines 8-20)

In spite of all this, Emma continues her parenting relationship with Dorothy forty one years after her death. This is clearly evident in the following example. Emma shares:

Every year I still hang her stocking up...I hang hers up still. Every year, I write her a little letter in December and I have all these letters that I leave in her stocking and I got them up in there from every year... that's something that helps me... one thing I do is hang up her stocking... because I can't buy her toys or buy her gifts or anything, so that's my way and I write her a letter. (pg 69, lines 9-12, 15, 23; pg 70, lines 1-2)

The continued parenting relationship is enhanced when parents receive comforting signs from their children. Signs parents describe receiving include the following: a) a peaceful feeling of their child's presence; b) dreaming of their child; c) smelling their child's scent; d) manipulation of electronics, such as lights, cell phone, and iPad; e) seeing certain animals, such as yellow birds; f) finding a penny engraved with the year that the child was born; and g) finding an object that has significant meaning. Joan describes what it was like for her to receive a sign from Joshua. In this example, Joan describes finding an object that has significant meaning for her. Joan explains:

When Joshua was in 4th grade, ... he had to write a fiction story about...if he found a genie in a bottle what would his three wishes be...He was just diagnosed at the time....He wrote this story that he and I were walking on the beach and he found this lamp and he rubbed it and genie came out and the genie said 'ok since you raised me, you have three wishes'. ...I took his first wish and I said, 'Oh, I wish for diamonds' and he said, 'Oh mom, don't wish for diamonds. I'll buy you diamonds. Let me have the three wishes'. So, he wished for whatever he wished for in the story. And it was this beautiful story. His third wish was that he was healthy and he lived a long life. And, of course, that didn't come true. So, anyhow, his teacher called me and said, 'Did you read this?' and I said, 'No', so she sent it home. I always kept it. I have it framed on both sides. I have it framed upstairs... I picked [my daughter] up from school...and...I was rushing to get to school and I was really thirsty and so I pulled over at one of those Subway shops to get a soda and I got out of the car and I saw something shiny. So, I picked it up and I really didn't have time to look at it. It looked like a ring and I said, 'Oh, maybe I'll find a kid to give this too'. I stuck it in my pocket and got my soda and I went to school and I got my daughter and I came home. That night I took the ring out of my pocket to see what it was and it was all full of something, wax or something. So, I cleaned it around. I spent a little time on it and I looked at the shank of the ring and it says '14 karat gold'. I said, '14 karat gold? This is really weird'. So, I went to the local jewelry store here and it was a stone on top of the ring, like an engagement ring. And, I said, 'What is this?' And they said, 'Well, it's \$65 to appraise it'. And so I said, 'Well, I don't want you to appraise it. I just want you to tell me what is this'. And they said, 'It's 14 karat gold and it's a diamond that's 1.5 karats. But there's like a big flaw in the diamond'. I said, 'Ok, whatever'. So I came home and told my husband, 'This is someone's engagement ring. I don't want this ring. It's not mine. Somebody lost their engagement ring. It means something to them'. So [in the paper] ...I put 'Found diamond ring, Subway location, [Amagansett NY]. If you can identify it, it's yours'. I don't want somebody's engagement ring! I would hope that somebody, if I lost my engagement ring that somebody would return it to me. I don't need somebody's engagement ring. Then I called the local police dept and I said maybe somebody called you inquiring about this ring. I found this ring and I told them about it and they said no but we'll keep your name on record. And, anyhow a few months went by and nobody else claimed the ring. I called the police dept back and they said, 'Well, it's yours'. The guy's like, 'Lady, I can't believe your calling me again. You found this ring, just keep it'. I'm thinking, 'I don't want the ring. It's not mine!' Why do I? So, I kept it. And then I realized a few years later, that it was a diamond that Joshua was talking about in his fiction story that he wrote, 'Mom don't worry, I'll buy you diamonds. I'll get you diamonds'. And when I looked at the diamond, [I

thought] ‘children are diamonds in the rough’ and [then] I realized this ring was from him...it took me years to put it together. But I was open. I was willing to be open-minded about it...I can’t imagine where else this ring came from and so that’s like a big sign. (pg 67, lines 22-23; pg 68, lines 1-23; pg 69, lines 1-23; pg 70, lines 1-8)

Peter describes what it was like for him to dream of Robert. Peter explains:

I don’t know where this falls if it’s spiritual, or wishful thinking, or hoping beyond hope, but one day I had a dream...I had a dream that I was doing something in front of my house and I put something on the windowsill. What I happened to put on the windowsill was an explosive and it blew out the window. I went inside to see the damage and my son was sitting in my chair with glass all over him. And I could feel that my mother was behind me and I didn’t see her, but I could feel that she was there. And...a couple of times he said, ‘I’m ok Dad. I’m ok. Dad, I’m ok’ and like that it was over. It was gone. It was off. It was done. Was that my wishful thinking or my epiphany from God? ... at that point I’ll take it...Some [bereaved parents] will go to a psychic...some don’t leave their home...some go to the bar and everything in between...I don’t know, but I take the ones where I can get them...I have no rhyme or reason. It was nothing that I went to bed thinking about...that’s the oddest thing that’s happened in the last year. And that’s mine. (pg 23, lines 21-22; pg 24, lines 4-13, 16-18, 20-22)

Like Peter, Doris has dreamed of Cindy. In one of Doris’ dreams, Cindy was in a room calling out to Doris, they ran toward one another, and Doris held Cindy’s hand for a brief moment (pg 113, lines 15-17). Doris explains what this dream was like for her, saying “I woke up and I was crying and I think it was because it was a fleeting moment and it felt so good to hold her hand” (pg 115, lines 2-3). Doris is comforted by her dreams of Cindy and wishes she had more of them (pg 114, lines 12-17, 19, 21; pg 115, lines 1-5, 7).

Like other bereaved parents, Kelly longs for signs that come in dreams. Kelly explains:

It came up in the [support group] discussions...that we long to have that connection. It can only be once or twice or whatever, but I think that's what we're all longing for...the only thing I want is I want Sam to come through to me. So he knows I'm alright...I just want him to come through in a dream. Sam, talk to me. Maybe then I'll accept it then. (pg 30, lines 21-23; pg 98, lines 17-20)

While Kelly has not dreamt of Sam, she has received a sign through the sense of smell. Kelly explains, "I must admit I've smelt Sam... It was like a smell about him. It was like really sweet. So, I've smelled him, but I haven't seen him" (pg. 28, lines 8-9, 16-17).

Kelly has also received signs in the form of electronic manipulations. Kelly shares the following example of a symbolic sign which she received that holds special meaning:

I think he's done some crazy things at home, weird things at home...I will tell you a funny story...the iPad was a very important tool for Sam [in the hospital during his illness] and it had an application on it called 'ghost writer' and basically it would come up with random words. I think Michael, [my husband], found it. It would come up with random words... apparently, it's supposed to spot like energy in the house, wherever you are. As I sit here, first time I ever put it on it came with 'cap'. So what? Ok, Sam only wore his cap backward. Well, then there would be 'airplane', 'island', 'purple'... you ready?, 'brain'... That was soon after. It wasn't long after Sam had passed. But to us, yeah, he is around. (pg 28, lines 18-19, 21-23; pg 29, lines 1-6, 15-16)

Sam had a brain tumor and made his Make-A-Wish trip to the Hawaiian islands just prior to his death. One of the last pictures Kelly has of Sam is that of him sitting in a wheelchair at the airport prior to boarding the airplane for the flight home. In this picture, Sam is wearing a purple shirt and Hawaiian lei of purple orchids around his neck. When Kelly showed me this picture during her interview, she

experienced a sense of peace as evidenced by a physical release of bodily tension and a loving smile as she gazed upon the picture which she saved as wallpaper on her cell phone.

Comforting signs such as these which the parents describe are documented in the after death communication literature (Guggenheim & Guggenheim, 1996; Daggett, 2005; Kwilecki, 2011). According to the After Death Communication Research Foundation, after death communication is “a spontaneous experience of communication with a deceased friend or family member” (retrieved from <http://www.adcrf.org/ADC%20Overview.htm>). In this study, parents experienced after death communications in the form of signs that hold special meaning and symbolize their parent-child relationship. For these parents, after death communications have enhanced their continued relationship with their child.

Parents actively continue the parenting relationship in a multitude of ways which help them to parent beyond the veil of death and maintain strong bonds with their physically absent child. In regards to the loss of the physical presence of a loved one, Root & Exline (2014) assert:

It is unclear, however, whether this physical absence must also signify the loss of the relationship once shared. Although death inevitably changes the relationship, perhaps the attachment may continue-albeit transformed- rather than terminate upon death. Perhaps an interpersonal connection could survive death, persisting without the physical presence of both members. (p. 1)

Findings from this study erase all doubt. The parenting relationship, built upon the deep, loving, interpersonal bond between parent and child, does indeed continue

throughout the parent's lifetime. The continuing nature of the loving relationship parents strive to maintain with their child is illuminated in the following reflection:

Love goes very far beyond the physical person of the beloved. It finds its deepest meaning in its spiritual being, his inner self. Whether or not he is actually present, whether or not he is still alive at all, ceases somehow to be of importance. (Frankl, 1959, pg. 38)

This study adds to the growing body of continuing bonds literature.

Conceptually, *continuing bonds* are an expression of "the presence of an ongoing inner relationship with the deceased person by the bereaved individual" (Stroebe & Schut, 2005, p. 477). Benore and Park (2004) refer to a similar concept which they term *continuing attachment*, defined as "the bereaved person's belief in an active, on-going relationship with the deceased...which connects the bereaved with the deceased in a way similar to that which relationships among the living do" (pg. 9).

There has been ongoing debate as to whether a continuing bond, or continuing attachment, is helpful or unhelpful to bereaved individuals. Some scholars assert continuing bonds can be beneficial (Klass, 1993; Klass, Silverman, & Nickman, 1996), while others raise concerns that they could be detrimental to grief resolution and psychological adaptation after loss (Field, Nichols, Holen, & Horowitz, 1999; Field, Gal-Oz, & Bonanno, 2003; Stroebe & Schut, 2005). Most recently, Field et al. (2013) quantitatively examined continuing bonds among 28 bereaved mothers who experienced either perinatal loss or the death of a child, aged 8 weeks to 18 years, due to various causes including suicide and homicide. The mean time since death was 2.02 years. While most mothers were comforted by their continuing bonds, a few

experienced distress. Those who experienced distress had illusory and hallucinatory experiences. This finding suggests that the impact of continuing bonds depends on the nature of its expression.

Findings from this current study show that parents demonstrate a variety of comforting continuing bond expressions. These expressions are evidence of the loving parenting relationship that they maintain with their child throughout their own lifetime. Parents in this study want to maintain bonds with their child and search for ways in which to do so. Suffering is exacerbated when their efforts are impeded. Whether others deem these parents' continued relationships with their children to be beneficial or detrimental is immaterial. What matters is the parenting relationship does in fact continue. Moreover, parents want the relationship to continue. As such, the continuing parenting relationship is one of the many essential aspects that make parental bereavement what it is. Without it, parental bereavement could not possibly be what it is.

Chapter VIII

SELF-RENAISSANCE

To experience parental bereavement is to experience a renaissance of the self. This self-renaissance brings change of great magnitude. A parent's self-identity and personality traits undergo radical transformation. Parents convert their true selves into their pretend selves. Further, parents' dreams for their children and for themselves also change entirely. As a result of these collective changes which parents experience in the wake of a child's death, parents experience a self-renaissance. That is, parents who are now completely and forever changed after a child's death experience a rebirth of self whereby they must reinvent who they are as a human being. Self-renaissance is a key aspect of the parental bereavement experience. A discussion of all that occurs in this self-renaissance follows.

Self-Identity

After a child's death, a parent's self is forever changed. Joan explains, "I'll never be the same. I'll never be the woman that I was prior to Joshua's death or illness. That woman is gone" (pg 46, lines 14-16). Emma explains, "You're really never completely the same again... You can never go back and be that same person again. You never, ever can go back" (pg 46, lines 2-4). Doris agrees that she too is forever changed, stating:

[My parents and sister] want me back. They want me to be myself again. They want me to be whoever that I was before Cindy died and I don't even know who that person is anymore. I don't know who the person is...that is talking to you anymore...your whole sense of identity changes. (pg 59, line 2-6)

For Peter, his entire self has changed including his exceptional mathematical ability, an attribute that he shared with Robert. Peter explains, "sometimes I feel my math skills have gone away too" (pg 3, lines 4-6). Math was a special part of Peter and Robert's relationship and a significant part of their father-and-son identity. When Robert died, Peter lost that part of his own identity. In this sense, a piece of Peter died with Robert.

After a child's death, parents identify themselves as bereaved parents. Sara explains, "I will always be a bereaved mother. I will always be a mother who lost a child" (pg 107, line 18-19). A bereaved parent may feel inwardly divided, as if one part of his or her self is frozen in time and another separate part journeys onward in life. Sara explains:

It's almost like even though you keep growing...you keep changing, you still think of that child at the age that they were. It's something that kinda keeps...a part of you...frozen in time...but the other part of you is moving on. (pg 92, lines 19-23)

For some parents, being a bereaved parent can sometimes feel like being nobody's parent. Since Cindy's death and her oldest son's departure to attend college, Doris sometimes feels like she is "nobody's mom" (pg 59, line 7) in the sense that core aspects of her being were directly connected to her identity as Cindy's mother.

Without Cindy's physical presence, aspects of Doris' self-identity have vanished.

Doris explains:

For the 12 years that she was alive...you are always somebody's mom. Your friends are their friends'... parents. You dine or go out to dinner or go to a show with people who...were parents of the kids on the swim team or who we knew from school or who we knew from church. And I don't fit in anywhere anymore. There's no nitch for people whose kids have died and if there is a nitch, no one wants to join it, and no one really wants them to join. (pg 59, lines 9-15)

It is not only a parent's self-identity that changes in this way, but also the parental unit's identity changes. Doris explains:

As far as my husband and I are concerned,...we went from being both working parents with active kids to now looking at each other and saying, 'ok now what?'...we will have been married 25 years...next summer...who are we now and where are we going now 'cause our day to day parenting is done...it's hard to find a place for, I say me, but most of the time I mean my husband too. I don't know how we fit...it's like we don't have a place anymore...we used to mark our lives with the kids and their activities...I love my husband and he loves me, but I think we don't know where we fit. (pg 72, lines 12-17; pg 80, lines 16-18, 20-23)

While part of what Deb describes is due to the normal developmental milestone that most parents encounter when grown children leave home, commonly referred to as empty nest syndrome, it is also directly related to Cindy's death. On account of Cindy's death at a very young age, Doris faces threats to her self-identity much earlier than she ever imagined she would. Doris explains:

Our son left for college last fall, so now we're...empty nesters –I'm trying to figure that out...I guess if I worked harder, maybe I could fit into the emptinester crowd which is where we would have been in a couple of years...I just keep saying, 'I don't want to be in that crowd. I don't want to be in that crowd'. I was still supposed to be...enjoying Cindy. (pg 55, lines 18-20, pg 88, lines 16-20)

Emma, on the other hand does not convey a feeling of being nobody's parent; rather,

Emma stresses:

I am still a mother of two children...I insist to this day that I have two children...when I'm watching TV, if I stay up a little while and they say, 'It's 11 o'clock do you know where your children are?',...I say, 'Yes, I know'. I know she's in Heaven and I know where my son is. That's your life now. That's the way you think...I am and I always will be...I am still a mother of two children. (pg 22, line 8; pg 45, lines 7-13, 19, 21-23; pg 46, lines 1-2)

On being a bereaved parent, Doris states, "I guess it's who I am now" (pg 71, line 7). On being a bereaved parent, Peter says, "there is no preparation for this and there is no hoping that it gets better. It doesn't get better. It's different...I know that's my lot in life. (pg 20, lines 20-21; pg 21, lines 7-8)

For Joan, being a bereaved parent is only part of who she is. Joan doesn't want it to be the "overwhelming thing that people see" in her (pg 18, lines 22-23; pg 19, lines 1-5; pg 29, line 5; pg 46, lines 10-16). Joan explains, "I work very hard at trying to...not be the woman who lost a child...I don't want people to look at me in the supermarket or at work and say, 'Oh, that's the woman who lost a child!'" (pg 46, lines 10-13). However, it should be not be mistaken that Joan is in any way implying that she has accepted Joshua's death. Joan explains:

I don't think you can accept the death of a child. I could never accept the death of a child, but...I'm as close to...knowing that he's not going to come back and knowing that I want my life to go on. (pg 46, lines 18-21)

After a child's death, a parent may question the normalcy of self. For example, in attempts to gauge her level of normalcy, Doris compares herself to other bereaved

parents, whether it is comparing the importance other bereaved parents place on their faith (pg 65, lines 3-6), the degree to which other bereaved parents pretend (pg 65, lines 7-11), or the intensity of other bereaved parents' grief feelings (pg 85, lines 13-15; pg 89, lines 14-17; pg 91, lines 20-23; pg 92, line1). Doris states:

I get up. I go to work. I do the best I can. I think I do ok, but I don't know what okay is! I don't know what normal is...I know that when I go out, I can put on my happy face. I call it my happy face and I can do what I need to do to get through the day. You know, perhaps when I see these moms who I think are doing so much better than I am, I wonder if they're not also putting on their happy face and doing what they need?...I know there is no normal in grieving, but I do wonder if I'm [normal]. I would like to be inside the heads of other grieving mothers to find out if they are like me or if I'm weird...how do you know that you are doing ok, that the way that you feel is acceptable or appropriate?...I don't know how to grade myself. I don't want to be too easy on myself either. I don't know how you know if it's ok to feel like crap or not. (pg 64, line 23; pg 65, lines 1-2; (pg 65, lines 7-11) (pg 85, lines 13-15 pg 89, lines 14-16 pg 90, lines 18-20)

Parents convey what might be considered a renaissance of the self, whereby they find they have to reinvent themselves after their child's death. Doris explains:

It's a real sense of being lost. It's like trying to rediscover who you are and what your life is about when you don't want to....the last thing I wanted was to reinvent myself...I don't want to. I want my child back and that's not happening...I know that but, this whole having to work through it all, sometimes...I just don't want to. It's almost like if I dig my heels in and I'm stubborn and I don't put on a face that maybe something will change and the only thing that changes is, of course, it gets more difficult. My brain knows that these are things that I just have to learn to deal with or learn to live with, but my stubborn side does not want to. (pg 74, lines 14-23)

Kelly echoes Doris' sentiments regarding the reinvention, or renaissance of self, when she speaks of her meaningful activities on behalf of children's safety. While she finds meaning in her efforts to keep children safe and hopes that some good

may come of her efforts, she explains “I don’t want Sam to have been the one who got the ball rolling” (pg 106, lines 9-10). Regarding self renaissance, Doris says, “I would rather have not done this” (pg 69, line 16). This has much meaning. Parents wish that parental bereavement was not their lived experience. They wish that their children didn’t die. They wish that they did not have to endure suffering and all that is part of the parental bereavement experience. Parents did not have a choice as to whether parental bereavement would or would not be their lived experience. Yet, the lived experience is real and encompasses all that parents describe.

The idea that a reinvention of oneself occurs after the death of a child is raised in the literature. The loss of a child precipitates a loss of parental identity (Umphrey & Caccitore, 2011) and forces a parent to redefine his or her identity with new goals and purposes (Barrera et al., 2009). This study advances knowledge of how a child’s death impacts a parent’s self-identity.

Self-Traits Change

Parents describe changes in their personality traits. After a child’s death, a parent may experience considerable self-doubt. Kelly explains:

I’m not myself anymore... I’m always doubting myself because of what I have been through the last couple of years. Now I’m doubting myself...I’m probably going to make a mistake... then you’ll get someone who makes comments. That is *so* [emphasis added] unfair! That is so unfair. (pg 108, lines 19-22; pg 109, line 1)

Here, Kelly is referring to negative, judgmental comments made by co-workers when she makes mistakes at work. For example, a co-worker once accused Kelly of

“sabotage” (pg 90, line 4) when she made a work-related mistake. Kelly views such comments as being unfair because the mistakes she makes are a result of decreased concentration which she has experienced since Sam’s death and are not driven by any purposeful intent. Since decreased concentration is a normal grief response that many parents experience in parental bereavement, Kelly feels it is unfair that coworkers pass judgment on her.

Although Kelly expresses self-doubt, she expresses a desire to have a full, vibrant life. Kelly explains:

I’m trying to do as many things as I can in my life ‘cause I know,... that’s the one thing I’ve learned is, how precious it is... my Grandpa’s nephew, he’s like 80’s, but he’s so feisty. He is so alive...oh my God, he is so *alive* [emphasis added]!...that’s how I want to be. (pg 110, 13; pg 111, lines 1-2; pg 115, lines 19-21)

After a child’s death a parent may become less motivated. Doris shares, for example, “My follow-through...I find crappy. I used to be...if you gave me a job I did it...I was dedicated...I cared...I don’t necessarily have that same drive as I once did” (pg 103, lines 2-4). After a child’s death, a parent may become more extroverted. For example, Sara describes herself as being introverted prior to Adam’s illness and death (pg 18, lines 11-17; pg 53, lines 2-4, 6-7), whereas now she is more extroverted serving as an advocate for important issues (pg 18, line 17-20; pg 53, lines 9-13, 15-17), including ensuring Adam received the best quality of care (pg 19, lines 3-23; pg 56, lines 14-16, 18-20, 22-23; pg 57, lines 2-6, 8-10, 12, 17-20; pg 58, lines 1-3, 5-6, 8-11, 13, 15, 17-22; pg 59, lines 1-10, 12-13, 15, 17-19, 21; pg 60, lines 1-2; 4-7; 12-

15, 17-19; pg 61, lines 9-17, 19-22; pg 62, lines 3-4); ensuring her surviving children receive the best education, testifying before her state's House Education Committee, and speaking at the Governor's press conference (pg 54, lines 20-23; pg 55, lines 1-2, 4-6, 8-10; pg 55, lines 10-14, 16-20, 22-23; pg 56, lines 1-2, 4-5, 7-8); serving as a leader within the childhood cancer community (pg 18, line 20-23; pg 20, lines 1-5, 7-9; pg 53, lines 17-18, 20-23; pg 54, lines 1-2, 4-10, 12-14, 16-20; pg 66, lines 16-20; pg 67, lines 1-3, 15-19); or advancing knowledge through participation in this nursing research study (pg 37, lines 11-14). Of her transformation from introvert to extraverted advocate, Sara states:

I think sometimes when you go through something like this you just realize that, if something is important, you only have so much time to do something about it. So you can either sit back and wait and see if someone else is going to do something about it or you can...step forward and speak up...When I see an issue that is important, that matters to us, I'm not going to sit back and be quiet anymore. I'm not. So, if I need to say something I will...having a voice at this point is a very important thing...that is something that I never really saw something before that was important and now, I do see...whether it is to help you or to help someone down the line. (pg 54, lines 16-20; pg 56, lines 10-12; pg 62, lines 11-16, 18-20; pg 63, lines 1-3)

Parents also describe changes in their parenting traits. Joan, for example, became more lenient in her parenting style. Joan explains:

I have these two little kids now and I try to be a little more lenient when it comes to some things. I try to take them out of school occasionally, go to a movie or I took my little girl to the beach last week. It was just her and I. 'Cause I know that life is short and it could be shorter than we ever think it could be...She hadn't missed a day of school like the whole year and I say 'you can't have perfect attendance, that's silly attendance, so let's go to the beach. So we went to the beach...I try to see things differently now. I try to say to myself all the time how important is it...that their room is clean or that...they get an A and not a B? Is it gonna change their lives? Like, let's be a little more

relaxed. You know, [it's] *very hard* [emphasis added]! Really hard. I try...so we have two ice creams a day and not one...I think that's what this experience taught me...live right now. Don't wait. (pg 20, lines 1-15)

Kelly, on the other hand, became more cautious due to fears of losing her other children. Kelly explains:

I've had a few panic attacks...I don't know if that's because [since] we lost Sam [I worry] that am I going to lose my other children, that I've become more neurotic, but [I'll ask,...] 'Whatcha [*sic*] doing?' ...more so than the regular parent would do probably...if I was to lose my second child...that would be it. I'd be done. There's no way I would go through two, no way. (pg 109, lines 10-16)

Parents' personal views about death can change after the death of a child. Prior to Adam's death, Sara was fearful of the death process. Now, however, she is no longer fears death because of a deeper faith that came from holding Adam in her arms as he died. Sara explains:

Before all of this happened, if someone were to ask me, if I'm being honest, I would have said I was afraid to die not because I'm afraid of eternity but because I was afraid of going through the death process, just not being sure of that. Now...I can say, because I held my son in my arms while he died...I am not afraid of dying because of what I have seen. (pg 42, lines 20-21; pg 43, lines 1-4, 7-8)

Joan was not afraid to die in early bereavement years, but is now. Joan is not sure if this is due to an evolution of her grief over time or due to other life experience's such friends of her age who are dying, but nevertheless Joan says "and so now I'm afraid to die...but for 13 years, I wasn't afraid to die" (pg 76, lines 12-20).

True versus Pretend Self

In parental bereavement, parents often assume a pretend self to shield themselves from an onslaught of judgment, to carry out daily responsibilities, and to protect others. Several parents in this study describe their use of pretending. Parents pretend by masking their true feelings. When parents pretend, their outward appearance is in opposition to how they feel on the inside. In this way, parents' pretend selves conceal their true selves. Pretending is not without consequence. Pretending depletes parents' energy and thus, increases their level of fatigue.

Pretend to protect themselves from judgment of others. Parents pretend to protect themselves from others' judgment. Kelly explains why she pretends to avoid judgment and how pretending contributes to her fatigue. Kelly states:

I'm also getting to the point where, especially with friends, and this once again came up in [support group] discussion...now you're lying to people. [People ask,] 'How you doing?' [I answer,] 'Oh, great!'...Now I'm a liar because you don't want to be labeled as a miserable person. So, how we look and how we feel inside is a total false...a total false...a lot of people [in the support group] were feeling like that they couldn't be themselves because of other people thinking of what you're like, what you're doing...Work has been awful...it's so difficult...with the people I work with...I certainly don't let them see [my unhappiness] at work. I do not. And there's a pretense. There's one right there. That's why I get...so tired... the way I [truly] feel sometimes, you would never dream. (pg 35, lines 5-9; pg 36, line 15; pg 37, line 23; pg 38, lines 1-2; pg 120, lines 1-2, 4, 6-7; pg 121, line 2)

Kelly is concerned that people perceive her as being "stupid" (pg 115, lines 8-9, 11-14, 16) and "crazy" (pg 56, lines 14-15; pg 115, line 19). Kelly states:

What do we do? Are we going to be in the loony bin? I don't know. Is this going to be labeled 'crazy'? I don't know...do [people] say I'm stupid?...Seriously, how do other's perceive us?... 'cause if you were upset about [losing] a child...that would never make me distant from you... 'oh that

woman's stupid, her child passed away' ...no, no, no, no, no, it wouldn't be me...but yeah, so that is a problem. (pg 62, lines 7-8; pg 115, lines 8-9, 11-14)

Kelly wants people to understand that nothing is normal and to accept her true self (pg 62, lines 2-6; pg 111, lines 11-15).

Like Kelly, Peter also dodges the 'how are you?' question. Under pretense, Peter answers, "I'm fine" (pg 19, line 3). Peter explains, "I just kind of leave it like that. I don't want to tell them... it doesn't do me any good... I just won't tell anybody else" (pg 19, lines 3-5' pg 47, lines 9-10).

Doris worries that if she stops pretending and becomes her true self people will pass judgment. Doris explains:

I feel like...if I'm honest about how I feel... I think I could scare people right the heck away! I sound like a *horrible* [emphasis added] person! You probably wouldn't want to see me on the street, but I'm really not a horrible person, but I sound like one. I feel like you must hang up the phone and go, 'Holy cow, she is crazy!' (pg 135, lines 12-15. 17-18, 20)

With reassurance that their true selves were most welcomed, parents set aside all pretenses during their interviews and, without reservation, openly and honestly described their lived experiences of parental bereavement.

Pretend to carry out their responsibilities. Parents may pretend in order to carry out responsibilities. Doris, for example, pretends to be somebody that she doesn't always feel like she is in order to carry out daily responsibilities. Specifically, Doris pretends by putting on her "happy face" (pg 65, lines 7, 10; pg 66, line 17; pg 108, lines 14-16). Doris describes what it was like for her when she had to pretend by

putting on her happy face in order to give an 8th grade promotion presentation to Cindy's former classmates, saying:

I had to get up. I had to give this speech. I had to function while I was within that setting until I could make my exit. Because to be sad or to...cry or whatever, if I were to let myself go there, it takes away from the experience that those kids are having...I can sometimes force myself to go function, then I get out as soon as I can... so...I say to myself, 'You have to do this...you have to hold it together for an hour and a half'... I can force myself to...put on the happy face and do what I need to do, but at the end of that 90 minutes, I have to go...I didn't stay around for the picture taking or social side after the promotion. I did what I had to do for the ceremony and then I left. (pg 66, lines 3-4, 6-8, 11-12, 14-15, 17-21)

Just as Kelly wishes people would accept her true self, Doris also wishes people would understand that how she may appear on the outside is not how she truly feels on the inside. Doris explains:

I expect those who...I would consider closer friends...to know I am faking...that I'm just sort of muddling through...and so...when there's no acknowledgment of Cindy or how hard it's been [it's hurts]... I guess it sounds selfish when I say it out loud, but that is...how I feel....that certain people should be aware that yeah I'm doing it but I'm doing it because I have to and I'm a big girl and it's what's best for whoever, whether it be [my husband] or my son or...or whoever. (pg 108, lines 21-22; pg 109, lines 2-6, 8-10)

Pretend to protect others. Parents also pretend in order to protect others. For example, because Doris is sensitive to other people's feelings she will pretend in order to protect them. Doris will guard her emotions when she is around Cindy's friend, Mary, because Mary gets upset when she sees Doris sad (pg 110, lines 6-10). There are times that Doris struggles with the desire to be truthful versus the need to pretend. Doris explains:

I'm not good at making the small talk because as soon as somebody asks me the ridiculous 'how are you?' question...if I'm feeling really sad, sometimes I get a little bit naughty...I'm tempted to say 'I feel like *crap* [emphasis added]!'...That's not really...fair...they don't deserve that from me, but sometimes I feel like I've lost the biggest thing in the world and I don't really want to pretend right now...but that's not right. That's not fair to other people...It's not very nice and I don't want to be a not nice person. (pg 67, lines 1-2, 4-10, 12, 14)

Joan also pretends to protect others. Rather than talking about Joshua and her true feelings, she avoids the subject. Joan explains:

As soon as I say I had a child who died, *whoa* [emphasis added], the whole room gets depressed!...If I'm in a party situation and everyone gets depressed, then I feel guilty. I just ruined a whole party by talking about this...if it's a one-on-one kinda of thing and I tell somebody, especially if it's another [bereaved] mother [that]...it's part of who I am,..they understand it, of course...maybe it will explain some of my bizarre behaviors occasionally like taking my kids out of school to go to the beach or whatever...I used to tell people more frequently in the beginning 'cause I wanted everybody to know him and then I reached a point in my life that I realized many of the people in my life now never knew him and that feels really sad. That's really sad 'cause he meant so much to me. But there's nothing I can do about it. I can't change it...it's too bad. (pg 28, lines 17-18; pg 29, lines 1-13)

Dreams of a Future Never to Be

In parental bereavement, parents consider dreams of the future that are never to be. The dreams parents have for their children and for their own selves are lost after a child dies.

The child's future. When a child dies, the dreams a parent has for the child's future also die. Examples of the types of dreams parents had for their children include, developing from children to adolescents and adults, graduating from high school and college, being in school concerts, going to prom, going to homecoming,

receiving confirmation, buying a first car, getting married, becoming a parent, becoming an Olympian, and pursuing a profession. Doris says, “[Cindy] wanted to be a nurse, a doctor, or a pastor...she might have been *you* [emphasis added]! She might have been the person...who was going to make a difference for people” (pg 50, lines 10-11, 13-14). A parent’s dreams of their child accomplishing life’s milestones such as these, as Doris explains, are “around every corner” (pg 83, line 15) and what makes the death of a child “the gift that keeps on giving” (pg 83, line 5). Many parents convey how much potential their children possessed. Peter states, “[Robert] could have been so much more than who I am and to see that wasted potential hurts...that goes over and over again, how unfair it all is.” (pg 1, line 20; pg 6 lines 16-18 pg 43, line 18).

The parent’s future. When a child dies, the dreams a parent had for their own self dies too. Parents’ lost dreams of their own future are intricately linked to the dreams they had for their child. For example, parents dreams include dancing at their child’s wedding, becoming a grandparent to their child’s children, hosting homecoming dances, buying their child a car, being the parent of their adult child, and enjoying the companionship, friendship, and love their child would bring them.

Emma states:

I see my friends that have daughters and the daughters take care of them and they do things together...it still hurts, that’s all I can say...I always think that if Dorothy had of lived [my life] may not have been any better, but I’m sure it would have been! I just feel like she would have been such a blessing. (pg 55, lines 18-21; pg 65, lines 12-15)

Parents never dreamed that their future would have included the parental bereavement experience. Joan states:

You know those commercials, ‘When I grow up, I want to be a nurse’, or ‘I want to be a teacher’? You know, my commercial ‘When I grow up, I want to be a bereaved mother’. A *bereaved mother* [emphasis added]! Who would have ever chosen this as part of their path in life? Ugh, how *horrible* [emphasis added]!...I can’t think of anything worse. (pg 73, lines 2-7)

Kelly states:

I never dreamed I would have ... held him in my arms. I held my deceased son...*Whoa* [emphasis added]!... *Whoa* [emphasis added]!...That is not right, not right. I always thought...I’m going to be...the mother dancing...with her sons at two weddings...so excited...so very excited...I’m never going to...dance with Sam at his wedding...and I just feel that that was taken away from me. (pg 45, lines 16-20; pg 97, lines 19-22)

Doris also thinks about her future dreams as Cindy’s mother that will never be, about which she feels “very sad, very cheated, very robbed” (pg 95, line 20). Doris explains:

There is just so much that I missed out from knowing...I wonder if Cindy would have been playing tennis now...or would she [have] started cross country?...Would she have been a mean girl? Because I would have had to put her in her place then. I don’t like mean girls...Would I have had to chastise her for too much [public display of affection]?...Would she have stayed her straight and narrow, black and white kinda self? Or would I be arguing with her?...Would she still have the same friends?...Would I approve? Would we get along? Would she and I have the kind of mother and daughter relationship that I...idealistically picture in my head? (pg 92, lines 22-23; pg 94, lines 1, 3-12, 14-19; pg 95, lines 1-5)

Doris wonders if her envisioned future would in fact be reality and says:

You could turn your deceased child into the perfect angel that they are in Heaven, but perhaps not have been if they were on earth... So you have this perfect angel in your head...like up on some perfect pedestal and then you have the reality of the situation. I feel like she would have made... mistakes, as would I...as her mother. (pg 95, lines 7-14)

Lost dreams contribute to suffering in parental bereavement. In a written expression of her parental bereavement experience that Kelly shared during her interview, she writes, “I miss the dreams I had for you and with you. I miss the future we will never have and the past, which, no matter how long it may have been, will never be enough” (Kelly, personal communication, May24, 2012, lines 4-6). The pain that Peter feels over the loss of Robert, the loss of the adult man his Robert could have been, and the loss of his own future as Robert’s father is indescribable. Peter says, “nobody could put it into words. There’s no words” (pg 6, line 20). Reflecting on his own parental bereavement experience, Apple (2008), bereaved father and author, writes:

The death of a child creates a domino effect. I can easily point to several other losses that came to us a result of our son’s death: future birthday celebrations, graduation ceremonies, wedding showers, wedding, first real job, baby showers, birth of a grandchild, celebrating holidays, new house celebrations, and the celebration of job promotions, just to name a few. The list of things we have grieved includes the loss of our dreams. (p. 82)

The self-renaissance which occurs after a child’s death includes changes in a parent’s self-identity, traits, and dreams. This compelling finding furthers understanding of how parents are intimately affected by and transformed by a child’s death, advancing knowledge of the meaning of the lived experience of parental bereavement.

Chapter IX

Journey Towards Healing Sustained by Support and Hope

To experience parental bereavement is to embark on a journey towards healing sustained by support and hope. This lifelong journey is yet another essential aspect of the parental bereavement experience. A discussion of nine underlying subthemes follows.

Healing: Learning How to Live with Loss

In parental bereavement, parents embark on a journey towards healing. Healing does not mean getting over the child's death or accepting the child's death. Rather, healing means learning to live with the loss of one's child. Both Emma and Sara explain. Emma states:

You have to learn to go on...you learn to live with it. You do, because there is no alternative...you're not going to commit suicide and the alternative is to learn how to live with it...you can start to learn how to live with it, but you never ever get over it...you never do get over it....you come to learn to deal with it and live with it, but it's a new kind of normal. (pg 30, lines 16-18; pg 46, lines 4-6)

Sara adds, "part of bereavement is learning to live again" (pg 107, lines 21-22). In a written expression of her parental bereavement experience, Sara shares, "pain does not lessen with time, by the way. But it is possible to learn to live in spite of it" (Sara, personal communication CaringBridge® journal entry pg 11, March 21, 2011, lines 4-5). Although a parent may come to learn how to live with the loss, healing is never

complete. Emma explains that the experience of a child's death is "something in your heart that is never going to heal completely" (pg 80, lines 5-7). Joan describes what her journey towards healing feels like, stating:

My heart was buried along with him. And now, I think my heart is coming back, but it's like...a sweater that has holes in it...there's like these holes in it. It's not a whole heart... it's...*torn* [emphasis added] and *tattered* [emphasis added] and it's *mutilated* [emphasis added] and *squished* [emphasis added] and it's not in the *right place* [emphasis added]...I don't know if it will ever be whole again. I don't know if I ever *want* [emphasis added] it to be whole again. I think it's part of my battle scars. (pg 30, lines 13-15, 17-21)

Healing is a lifelong journey in which parents, forever scarred, learn to live with the loss of a child.

The journey towards healing is arduous. Joan and Kelly offer insight.

Although Joan equates her experience to being locked inside the gates of hell, she also shares that she was able to leave this place of extreme suffering and journey to a place where suffering is less intense. Joan states:

I managed to get out...I don't know how...Let's face it, this is my life...as far as I know I'm only coming through this life once and I could... stay in that black hole, but what was that going to do for me?...I couldn't move out of that black hole until I was ready but I had to move out of it for my own good...for *my life* [emphasis added]... I managed to get out. I don't know how. I really don't know how...I don't know how I got here. I'm ok. I'm not 100%. I'll never be 100%. But I'm ok. I'm functioning. I'm trying to live. I'll never forget my son. Of course, I'll never forget my son. (pg 10, lines 11-15; pg 26, line 13-16)

Kelly offers additional insight of the arduous journey towards healing and describes what it has been like for her to climb out of the hole created by the destruction that followed Sam's death. Kelly describes the climb out of the hole as being "a work in

progress” (pg 92, line 17). Kelly is able to take a step up from the bottom of the hole when she feels happy (pg 139, line 6-7), when she feels peace (pg 139, line 12), or when something good happens (pg 92, line 21; pg 93, lines 7-8; pg 107, lines 21-22; pg 108, lines 1-5). Kelly explains:

[A] step would be something that’s good that happened...something really worked well today...I credit everything to Sam. If I had a good day, I thank him. So that to me is a step. If anything good today happened, is a step. (pg 92, lines 21-23; pg 93, line 1)

When something good happens, Kelly feels a sense of lightness (pg 108, lines 3-4), a sense of relief (pg 107, lines 20-21; pg 108, lines 1-2), and can smile (pg 107, line 21). As an example, Kelly describes a specific instance when she was walking on the beach and felt Sam’s presence (pg 139, lines 10-13, 17-20, 22-23; pg 140, lines 1-2, 4-10). She describes how she felt in this particular moment, saying: “[I] felt a relief...*wow* [emphasis added]...there was *sunshine* [emphasis added], there was the *water* [emphasis added], it was so *peaceful* [emphasis added]. That was pure happiness. I shouldn’t say happiness...peace. Like peace of mind...I wasn’t feeling that heaviness...that felt good” (pg 139, lines 11-13, 20). But as Kelly tries to step up out of the hole, situations come along and push her back down to the bottom of the hole. It can be something as simple as Sam’s picture being knocked over by the dog wagging his tail (pg 108, lines 5-10). It can be visiting family members who have not maintained a supportive presence (pg 110, lines 20-22). It can be having a difficult day at work because it is difficult for her to concentrate (pg 108, line 15) or because judgmental co-workers are critical of small mistakes she may make (pg 90, lines 3-5,

7-9, 11-12; pg 93, lines 1-2, 9-10; pg 121, line 5). When Kelly is back at the bottom of the hole, she starts the climb back to the top once more (pg 93, lines 4-15, pg 94, line 1; pg 139, lines 5-6). Kelly explains: "I've got to figure out how to get back up, which may take a couple of days...but I know I'll start climbing again...I've got to figure out how to climb again" (pg 93, lines 4-5; pg 94, line 1). She says she tries to stay active (pg 134, lines 15, 18) and is taking "baby steps" towards learning every day how to exist without Sam (pg 112, lines 12, 14-17; pg 114, lines 1-2; pg 116, line 14). With conviction, Kelly says: "I know I've got to do it...I will conquer. I *will* [emphasis added] conquer." (pg 112, line 17; pg 121, lines 3-4). Kelly is on her journey toward healing, just as Joan is. Joan shares:

I never thought I would recover. I thought I was going to be that person forever, that really that I was going to be in that place...there was this one couple who came by and they lost a child like maybe 30 years ago to leukemia and she looked at me and she said, 'You're going to be ok'...I wish I could have said to her, 'Get out of my house. I'm not going to be ok. You've got no idea what you're talking about. I don't know how you are ok. I will never be ok'. And I am. I'm ok. I'm really ok. I mean, I think I'm okay anyhow...I'm way different that before this experience happened, but I'm ok...I think it's because I got to a certain point and the cells in my body changed and I think they kinda got rid of the grief, little by little by little. (pg 52, lines 21-23; pg 53, lines 1-9)

For some parents, the journey towards healing often means living *in* and *out of survival mode*. For Sara, being *in survival mode* means "just putting one foot in front of the other and just making it, just going from one thing to the next, just doing what needs to be done" (pg 14, lines 22-23), not caring about "the normal everyday things like eating, housework, laundry" (pg 14, lines 1-2), and "basically kind of crashing in

between...everything that has to happen” (pg 97, lines 20-21). Survival mode is a more long term state of being. Sara’s first experience of being in survival mode came during the first six months after Adam’s death when simply getting out of bed (pg 12, line 14-15; pg 15, lines 14-15, 20-22; pg 16, lines 2-3, 23) and showering (pg 16, lines 6-13) were difficult to do not because any purposeful decision, but rather because she wasn’t even thinking about such everyday activities that always used to be part of her self-care routine prior to Adam’s death (pg 15, lines 12-13). When in survival mode, everything takes more effort to do. Sara offers the following example:

If we were ever going to go anywhere...it was fairly common for us at that time to be late. It was almost like a dread for me just to leave the house, or just everything was more of an effort. Even though I knew we needed to be somewhere at a certain time, I think it was almost like having a new baby, where you don’t realize how long it’s going to take for you to get ready. (pg 17, lines 2-7, 9-10)

Sara moves into survival mode during overwhelming times, such as during the first six months after Adam’s death (pg 8, lines 1-2; pg 14, lines 4-5; pg 100, lines 18-22) and during the holidays which coincide with Adam’s diagnosis and death anniversaries making the end of the year a particularly “heavy time” (pg 15, lines 1-9; pg 94, lines 21-23; pg 95, lines 1-3). Going in survival mode even happens during challenging times that are not a direct result of her grief associated with Adam’s loss, such as when concerns about a family member’s health arise (pg 15, line 10; pg 98, lines 3-7) or helping her older son finish school and bringing him to camp (pg 99, lines 13-16). For Kelly, living in survival mode means “you’re just surviving today...just get up and

go...that's it...get up and go" (pg 43, line 5; pg 64, lines 15-16). For Kelly, living in survival mode is analogous to pushing up against a brick wall. Kelly explains:

What is [survival mode] like? ...Ok, here's your day [holds hand up with palm out]...You got a wall. Feels like you're pushing against a wall, every day 'cause it's going to be no different. Like I said, the outcomes are [not going to change]...I can't bring Sam back. I cannot bring Sam back. So, it's like your pushing your head against a brick wall for no reason. 'Cause you know in reality that it doesn't matter what you do, you're not gonna bring Sam back. (pg 59, lines 14-19)

Sara describes what living out of survival mode is like, saying moving out of survival mode means "living" (pg 8, line 7; pg 107, line 21-22; pg 78, lines 15-16). Sara explains:

We are moving through whatever it is that we're doing and everything that we do is not...always centered on the fact that we lost a child or that we had a child that battled cancer...our thoughts are not always there. (pg 78, lines 16-19)

Sara does not feel guilty for living, but she does wish there was more "time to just sit and think more...and not have it make it difficult to get through the day" (pg 78, lines 14-15).

Self-Care

Self-care behaviors can help parents along their healing journey as they learn to live with the loss of their child. Parents often explore different self-care behaviors in order to determine which will be most helpful. Parents have tried the following self-care behaviors: a) writing; b) reading grief literature; c) reading contemporary fiction as a distraction; d) talking aloud to their child and to others about their child; e)

attending to personal health conditions; f) discontinuing prescribed medications for grief symptoms and mood-altering substances, such as alcohol; g) physically releasing grief emotions, such as screaming as loud as possible and throwing objects; h) exercising; i) getting a pet; j) having more children; k) avoiding other people's children; l) applying permanent makeup; m) minimizing exposure to negative situations and news coverage of catastrophic world events; and n) attending support groups.

Parents have had varying degrees of success with these self-care behaviors. Many parents have found talking to be helpful. Parents find it helpful to talk aloud to their child. Kelly shares, "the new norm for me is to talk to Sam at night and that gets me through most of the day without crying" (pg 115, lines 2-4). Talking aloud can be done with audible vocalizations. Kelly provides an example of how she talks aloud to Sam, just as she talks aloud to her other children, Tom and Mary. Kelly explains, "Saturday was, of course, an errand day so I would [say,]... 'Tom, how you doing?' I'm ok. 'Hey Mary, how you doing? All buckled in? Good' and 'Hey Sam, how 'bout you, how you doing?'" (pg 36, lines 22-23; pg 37, line 1). Talking aloud can be done without audible vocalizations. Doris describes an example of how she talked to Cindy. Doris explains, "I did have a discussion out loud in my head the other day, blowing drying my hair, and I was pretty sure [Cindy] wouldn't like my hair this short" (pg 116, lines 6-8). Talking aloud, with or without audible vocalizations, minimizes intense grief and strengthens the connection parents feel with their child in

their continued parenting relationship. Parents especially find it helpful to talk about their child with other people. Emma says, “Just talking about [Dorothy] helps me” (pg 8, line 14). Kelly also finds talking helpful and says “I could talk about Sam every night” (pg 69, line 20). Talking about their child with other people helps because it acknowledges the child’s existence and supports the continued parenting relationship. Emma explains, “you want people to know that she did exist and she was and is still my daughter” (pg 14, lines 11-13). In addition to talking, many parents find writing to be helpful.

Writing helps to relieve grief symptoms, serves as a communication mechanism, and facilitates continuation of the parenting relationship. Some write letters to their children. Some write stories or journals about their experience. Sara, for example, writes in a journal posted on Adam’s CaringBridge® website. CaringBridge® is a nonprofit organization that provides a health social network where families can create a personalized webpage and connect with others, share news, and receive support (retrieved from http://www.caringbridge.org/assets/pdf/corporate/caringbridge_mediakit.pdf). Sara shares the following about her writing:

I continue to write after [Adam] died...I haven’t written much recently but I did write. There are still things I want to write about that I never did write about and I probably will...I call it ‘grief writing’. I did do some grief writing there afterwards and I tried to be careful about what I wrote because in the back of my mind always was that there are a lot of families that look to me for support and I didn’t want to bog them down with my grief. Especially the new families, so I think I was actually a little more particular about what I put on the board site than some people are. But for me it was a good outlet for a

while. I do have more writing that I want to do...Sometimes I have the energy to write and I don't have the words...Other times, I have the words and I don't have the energy...Sometimes, I have both but I just feel like it's not the right time because of something that is going on in the brain tumor community. (pg 27, lines 8-22)

Writing has been helpful for many parents, though not all. Doris, for example, explains:

I haven't found journaling to be successful for me. I've never been a great journal person...I like pretty notebooks and whatnot, so I have a lot of them...and that's about it. I'm just not disciplined I guess. I always think well maybe it would help if I forced myself to do it...There's all these things like, 'Sixty days to feeling better', or five minutes of meditation in the morning and then writing and thinking things through the day and writing at night...I plain forget sometimes. I don't know if it's that I'm not committed enough...I have not made that a part of me yet...Maybe I should...If I really tried to commit to something like that,...maybe there's comfort there that I...I don't know about because I haven't [committed]. (pg 116, lines 10-11, 13-14, 17-21; pg 117, lines 1-3, 5-7)

In spite of the helpfulness of self-care behaviors, they are hard to do. Not all parents may want to practice self-care nor have the wherewithal to do so. Kelly, for example, wishes she took more time off from work but was unable to do so because she was her family's primary financial supporter. Kelly states:

I...didn't take the time off that I should. I should have taken far more time off. And I would stress on these people, take time off...I didn't know that until after...It's so important, so important. I would definitely stress to other parents that have to work, take time off. Take time off. Go to HR. Do medical leave. Do something, but take time off...stress more time off for these parents (pg 39, lines 19-23; pg 40, lines 1-4, 11)

Kelly's emphasis on a parent's need to take time off from work after experiencing the death of a child merits attention in light of the current, ground roots effort spearheaded

by bereaved parents to pass legislation that would extend the Family Medical Leave Act of 1993 (FMLA) to include employees who have experienced the death of a child. At present time, most employers permit parents two or three days of bereavement leave following the death of a child. After that, bereaved parents must use vacation time or risk termination if they require more time off. The Parental Bereavement Act of 2013, introduced and referred to a congressional committee on February 5, 2013, would extend FMLA benefits of 12 weeks of unpaid leave during any 12-month period to eligible employees who have experienced the death of a son or daughter (retrieved from <https://www.govtrack.us/congress/bills/113/hr515#summary>). This legislative amendment would better serve the needs of bereaved parents like Kelly. Kelly's lived experience provides supportive evidence of this fact. If more people better understood the lived experience of parental bereavement, how could the Parental Bereavement Act of 2013 not be passed by the Senate and House of Representatives and signed by the President of the United States?

Like Kelly, Doris also explains just how difficult it is to practice self-care and try, for example, exercising. Doris states:

You don't get enough sleep. You're not getting enough exercise. It's just kind of this evil cycle that is very difficult to climb out of...I feel bad about myself...I'm sad. I don't do anything about it and then I feel worse...I let myself get out of shape...I did go to my first boot camp exercise class...maybe today trying that boot-camp class it'll [help]...I don't wanna be like tooting my own horn, but that was *really hard* [emphasis added] for me to do! (pg 102, lines 16-17; pg 106, lines 13-14, 16-19)

So great is suffering, some parents have no desire to engage in healthy self-care behaviors. Joan explains what her experience was like:

I didn't care if I lived or died. I didn't wear a seatbelt. I started to smoke cigarettes...I didn't really care what happened to me at all... I could not take care of myself...when they buried my son, I just wanted to jump into the hole...and just stay there... I didn't care if I ended up in the hole and put the dirt over me, I mean that was going to be fine. I didn't think of anything after that. (pg 4, lines 19-20, 22-23; pg 5, lines 10-11; pg 49, lines 19-20, 23; pg 50, 1-2)

However, four years after Joshua's death, Joan made a conscious decision to live.

Joan doesn't know how she arrived at that decision or what gave her the drive to live, but she only knows how far she has come "only by looking backwards" (pg 64, line 14). Once she made the decision to live, Joan tried many different self-care behaviors such as those previously discussed. While Joan cannot pinpoint one specific thing that led to her decision to live, she mainly credits her faith (pg 49, line 14; pg 50, line 8; pg 51, lines 8-9) and a pure desire for her life to be different (pg 49, lines 12-13; pg 54, lines 17-19). Joan states, "I think I did it for me. I don't think I did it for anybody else...I made a decision that I did want to...die. I was *glad* [emphasis added] that I didn't jump in the hole" (pg 51, lines 1-4).

Support

Support is provided in many forms, both formally and informally. Formal bereavement support groups and individual counseling, as well as informal supportive friendships can sustain parents along their journey towards healing.

Formal support. Parents participating in this study receive formal support from in-person and on-line support groups. The Children's Brain Tumor Foundation (CBTF), The Bereaved Parents of the USA (BP/USA), and The Compassionate Friends (TCF) are among the bereavement support groups parents attend.

To provide some background, The Compassionate Friends was founded in England in 1969, established in the United States in 1972, received 501(c)(3) not-for-profit incorporation in 1978, and has grown from 40 to 650 chapters in all 50 states in the 35 years following its incorporation (retrieved from http://www.compassionatefriends.org/about_us.aspx). Bereaved Parents of the USA was established in 1995 and has 73 chapters in 33 states (retrieved from http://www.bereavedparentsusa.org/BP_About.htm). The Children's Brain Tumor Foundation's Loss, Grief, and Bereavement Program was established some time after the organization was founded in 1988 and offers support in various formats, including phone counseling and support; family to family network; as well as in-person, phone, and online groups (retrieved from <http://www.cbtf.org/connections/loss-grief-bereavement>). In addition, some parents have attended support groups offered through their place of worship. Some also receive formal support through individualized counseling

Parents emphasize the need for formal support. Kelly states it "has got to be an incredible part of healing and I didn't know this. I did not know. I tried to see if I could do it myself, but there is just no way...no way" (pg 43, lines 7-9). In a written

expression of her parental bereavement experience that Kelly shared during her interview, Kelly writes “communication and support is so valuable at this time. It was valuable when Sam was alive and even more so now that he has passed” (Kelly, personal communication support group parent questionnaire, May 24, 2012, line 6). Participation in a support group is helpful because it provides parents’ with the opportunity to spend time with others who share a similar experience. When parents attend support groups where they are surrounded by other bereaved parents, they feel better understood and feel less alone in their experience (Umphrey & Cacciatore, 2011).

Sara finds her support group to be very helpful, explaining:

[The support group is] probably one of the things that we look the most forward to in the week, every week. Because it’s one night, every week, that we know that we can focus on Adam and what we’ve been through and it’s not like we sit there and cry the whole time we are there or anything like that. Sometimes we cry, sometimes we don’t, but it’s just the idea that you are going to be around other families that also experienced a deep loss...it’s nice to be around other people who know what you’re going through. (pg 31, lines 14-19; pg 32, lines 2-3)

Similarly, Doris’ support group helps her feel less isolated because, as she explains, “you’re surrounded by people...who’ve lost children” (pg 61, lines 12-13).

Emma experienced this herself when she attended her first parental bereavement support group. Emma explains:

That was where I started to finally feel like things made more sense...I can remember the night I walked into the room for the first time and there were so many people there. And I just looked around and I just knew that every person there had lost a child. And I just felt like all of a sudden I was where people would understand and...that was a good thing...the amount of...parents that

were there...was mindboggling...every one of them has lost a child...this was one club that we wished there didn't have to be new members, but every month it was. Up until then, I never thought that much about going through something like that. But after it happened then you realize how many people are going through the same thing. (pg 6, lines 1-2, 9-13, 15; pg 58, lines 3-4, 7-11)

In addition to being surrounded by other bereaved parents, the support group can provide parents opportunities to participate in helpful activities.

Parents share examples of support group activities that they have found to be helpful. Kelly found the following activities to be a helpful part of her bereavement support group's summer camp: a) having parent and sibling designated support groups (pg 24, lines 6-10, 12-15); b) doing arts and crafts (pg 31, lines 2-3, 5-7, 9-10; 14-15; pg 128, line 22); c) having a day designated in honor of Sam where everyone at the camp wore his favorite color, green (pg 32, lines 15-16); and d) participating in a balloon release in which she was able to communicate with Sam by attaching a written note to the balloon addressed to him (pg 32, lines 12, 16-17); e) being out in nature (pg 31, line 14; pg 32, line 1; pg 128, lines 16, 18); and f) having pictures of some activities to bring home (pg 32, lines 2-3). Two activities Emma has found especially helpful in her support group has been the walking labyrinth and the memorial service. Emma describes the walking labyrinth:

It's like...a little walk that you take...it goes around and around until you get to the middle... in certain stops you [could] say a prayer or... it made you think a lot about things...once I got to the middle, I felt I had worked things out a lot, different things ...it was very peaceful, very, very peaceful...*oh my, that helped* [emphasis added]! Oh, that was just *wonderful* [emphasis added]! By the time you got to the middle, at least [for] me, I just sat down and I was ready to have a good cry!...it was so spiritual...I had never walked a labyrinth before. (pg 83, lines 17-20; pg 84, lines 1-7)

About the memorial service, Emma states:

Every year in December they have a memorial service on the first Sunday in December...I never miss that. It's very sad in a way and some people just can't do it, but to me it's something I do for my daughter. It's...one of the only things I can do and I go to that...for some reason it helps me....they say all their names and...one of the men put together a slideshow and after all of the readings and songs and all, they put all the pictures up on...this screen one at a time and...it just helps me a lot. It really does...everybody in that huge group...knows her name...it's...something that helps you. (pg 7, lines 16-17, 19-21, 23; pg 8, lines 1-4; pg 24, lines 10-11)

Emma acknowledges that some parents may not be comfortable going to a support group and talking about their feelings (pg 20, lines 15-17; pg 21, lines 5-10), but says:

You don't have to talk. Go and listen to the other people and you'll learn that you're not alone...even though you don't want other people to be in your shoes, it still helps you to know how they feel...you do have to push yourself a little, but it will help so much if you're open to it...I think that's the most important thing, is to just put yourself out there and go... it's just something that helps you...I would recommend to anyone. (pg 21, lines 6-10; pg 24, lines 8-9, 11, 13; pg 32, lines 21-22)

Frequency of parents' formal support attendance and participation varies. Some parents attend weekly support groups, while others attend monthly. Some attend biannual bereavement support camps. Some attend their bereavement support group's yearly memorial service. Some religiously read their monthly bereavement support group's newsletters when they are physically unable to travel to attend the group in person. Some appreciate their support group leader's extension of support when life's other responsibilities prevent frequent attendance. Others participate in their bereavement support group's online chat on a regular basis. Some attend

individualized counseling every two to four weeks, sometimes more often when they feel the need for additional support. Peter explains, “the reality of it is, this is your own and however you do it is how you do it” (pg 38, lines 8-9).

In spite of the helpfulness of formal support groups, parents may also feel isolated within the group because not all parents in attendance share the same lived experience. Specifically, not all bereaved parents who attend a support group have experienced the death of a young child to cancer. Joan explains:

[At] the turn of the last century, many children died... everybody knew somebody who had a child that died and...they could commiserate or...do whatever they want together, but now, thank God, children aren't dying like they used to from all those diseases like smallpox...I think it's rarer now that you come across a person who has a child that died and so there isn't that same camaraderie. So now we have to look for support groups and then even in the support group, like in my particular support group, I'm the only one who lost a child under 18 from cancer...there are people that lost children to suicide or motorcycle accidents or car accidents...and even a few who lost children to cancer but their children were 35, 40 years old...I think that's gotta be different too. (pg 35, lines 22-23; pg 36, lines 1-4, 6-13)

Peter feels similarly, stating “it's really kind of odd...yes, you're going through the same thing, but it's different” (pg 38, lines 4-5). Kelly wishes Sam's hospital offered a bereavement support group for this very reason. Kelly believes a hospital-based parent support group would be particularly helpful because parents have an existing relationship with hospital staff that directly cared for the children, parents have an existing relationship with one another, and parents share a common lived experience. Kelly explains:

Our hospital, that's the only thing they did not offer which is so unfortunate...They do everything else. They celebrate. They do everything. I

mean they go way and beyond, but they did not have no sessions. I'm like, are you kidding me with all the conference rooms and stuff like that? You don't have a session. I mean you know these kids. You know these parents. You know they become second family to you and you don't have a...bereavement group? We would probably all know each other...very, very, strong connections. (pg 66, lines 13-15, 17-22; pg 67, lines 1, 6)

Some parents participate in online bereavement support groups. Such groups afford parents the opportunity to communicate individually with the support group leader or to participate in an on-line chat with other parents and the group leader.

While online groups can be helpful, some parents feel left out when the discussion centers on the needs of parents who have recently experienced a child's death rather than on needs of parents who are farther into bereavement. Kelly describes feeling left out when participating in her support group's online chat with multiple participants.

Kelly states:

The only problem with that is if someone new came along, you're lost...because the new person wants to talk...and you're like in the background...I felt cut off because this new person that came on, they focus on the new person instead of like the regulars. So instead of being rude, I stayed on for a good hour or so, but...I didn't realize that that could happen and obviously it did...when there are a lot of people on...it's like you're in the background because everybody wants to know about the new person, which, don't get me wrong, its, its normal but before you know it you're in the background. And if you get ignored, if you say something and you get ignored, because you get lost in that chat but that's so easy. So even though I like it, I don't think it's the best. I don't think it's the best, especially when there is a lot of people, you do get left out. (pg 76, lines 3-5, 9-11, 13-20; pg 77, lines 1-3)

Some parents have attended formal, individualized counseling. Counseling has helped parents to varying degrees. While Kelly feels that individualized counseling is

so important that it should be mandatory for all parents, her sense is that many don't receive as much counseling as they need due to financial cost. Kelly states:

They've got to do something with counseling. They have to. It's got to be mandatory or something...how these other people function? I don't know. How do the other parents...feel? Do they feel that they should have had more counseling? 'Cause I think they're not going because of the money. How does anyone work through it? How does anyone work through ...the death of a child? (pg 40, lines 12-14, 19, 22; pg 41, lines 1-2)

Kelly has sought out counseling, though her husband has not. Kelly feels that while Michael "is totally depressed" (pg 94, lines 2-3), he "isn't ready for help yet" (pg 22, lines 8-9). Although Kelly finds counseling helpful, she knows it won't change how she feels. Kelly states, "Yes, I'm going to counseling...and it will help you for a while, but...it's not going to change how you feel inside, *ever* [emphasis added]!" (pg 103, lines 17-18).

Doris worries that counselors lack specific knowledge of parental bereavement; therefore, they could not understand her lived experience. Doris explains:

I think if I went to a counselor who didn't know anything about child loss specifically, I don't know if...they could understand...I just don't know what I would say...if I went to a counselor and they said, 'Have you tried this?' or 'Have you tried that?'. Well, *someday you can't put your pants on* [emphasis added]! (pg 90, lines 3-5, 11-13)

Doris wants health professionals to better understand parental bereavement so they can better support bereaved parents. Doris states:

I really hope that the work that you're doing...makes a difference for other parents because I think it's a lonely group and if more people aren't trained to assist us...there may be more of us that go off the deep end. (pg 90, lines 3-9)

Peter tried reaching out to a counselor for support three months after Robert's death (pg 37, lines 20-21). However, he stopped within a month's time because it was very difficult for him to do so soon after Robert's death (pg 37, lines 21-22) and because of his family caregiver's responsibilities (pg 37, lines 22-23; pg 38, line 1). Peter explains, "I haven't been able to make a coffee date, never mind anything else, so [counseling] went out the window pretty quick" (pg 37, line 23; pg 38, line 1).

Emma has found the support she receives from her counselor to be of immense help. Emma says the following about her counselor:

[She] is a wonderful woman...she's my lifesaver...she knows me inside and out...she's just so helpful and so kind and caring...I can talk to her about anything...she just seems like she understands and she will tell me some things about what she thinks about things...it's just really good. She has me come in a basis of how I am when I am with her that day. If she thinks I need to see her more often or less often. She's just wonderful. (pg 13, line 21; pg 25, line 23; pg 26, lines 1-2; pg 78, lines 6-10)

Informal support. Friendships are a source of informal support. Friendships with bereaved parents offer the most support. In later bereavement years, Emma developed many friendships with both bereaved parents and non-bereaved parents.

Emma says:

I have a whole lot of friends. My doctor she said I've never known anybody to have as many friends. Some of them are bereaved mothers like me and some of them aren't... I mean I enjoy all my friends but I especially enjoy the bereaved mothers. (pg 59, lines 20-22; pg 60, line 1)

Emma has become friends with Carlene, Lila, Nadia, Jennie, and Rosita, each of whom are bereaved mothers Emma met through her support group (pg 6, lines 19-22; pg 22, lines 1-2; pg 28, lines 8-15, 17; pg 33, lines 11-21; pg 34, lines 1-2, 5, 7; pg 57,

lines 7-23; pg 60, lines 1-13, 15-23; pg 61, lines 1-8, 10-22; pg 62, lines 12-13, 21-23; pg 63, lines 1-3, 5-9, 12-14, 16-23; pg 64, lines 1-2, 4-7, 12-14; pg 80, lines 13-16; pg 83, lines 8-10; pg 84, lines 7-9, 11, 12-23; pg 85, lines 1-2). Emma says, “I have over the years, I have made other friends, but... my ladies from the bereaved parents things are my special, special friends...that’s the most comfortable group...It’s wonderful! I would hope that...other mothers could find that” (pg 33, line 21; pg 34, lines 1-2; pg 62, lines 12-13). Emma is able to share her lived experience and enjoy their company. Emma explains, “we can talk about each other’s child or our child. We can also talk about other things. We laugh together, which... at first...was hard” (pg 60, lines 9-11).

Over the years, Emma and her friends have enjoyed various activities with one another (pg 60, lines 19-20), such as starting a book club (pg 61, line 22-23) and hosting dinner parties (pg 60, lines 3-9). Emma shares the following example:

We started a little book club...we read a book called, ‘The Help’, and a month or so after that Carlene got the movie and we all went to her house and had pizza and watched the movie... we do things like that...they’re just fun things to do (pg 63, lines 22-23; pg 64 lines 1-3)

Emma says, “we share a lot and...we get together periodically” (pg 6, lines 21-22).

Emma especially enjoys their Christmas pot-luck dinner party they have every December (pg 61, lines 7-8, 10-16; pg 63, lines 5-9, 12-14, 16-22; pg 64, lines 1-2, 4-7, 12-14; pg 72, line 16). Emma explains:

At Christmas time in December, we always have at my house...a big dinner... we plan a menu and everyone brings a different dish... we sit and talk and we

can mention our children. We can laugh about things they did and we understand one another. (pg 18, line 23; pg 19, lines 1-3, 5-6)

Being with friends in December helps Emma endure intense grief that November brings. Emma shares:

I have a sunroom that I had put on the house...I have it all decorated...It is pretty out there...When we finish eating, we move into the living room and open our gifts. And later we have dessert and coffee. It's just something that I look forward to so much...it's only a couple weeks after Thanksgiving which is hard...it's something nice for me to look forward to. (pg 63, lines 20-21; pg 64, lines 1-2, 4-7)

These friends have also been present for Emma to help her to endure the immense waves of grief throughout her parental bereavement experience. For example, Carlene supported Emma on the day of her mother-in-law's funeral by making herself available to take Emma's telephone call during work and listen to her (pg 9, lines 9-23; pg 57, lines 7-23). These simple acts of being present and listening helped Emma to endure exacerbated grief. About Carlene, Emma says:

[Carlene] and I are the best of friends now. That day though, I really didn't know her that well then ...her husband had said she already left for work and he gave me her work number...I told her I just don't think, I don't know if I can do this, but I knew I had to because I really loved my mother in law and I wanted to go. I mean I wanted to give my respects, but I said '[Carlene], what am I going to do?' So she talked me through it and I was able to [go]...but I've never forgotten that. She's always been such a good friend. (pg 57, lines 7-19)

Emma adds:

We were talking one time about how the people in your life... you probably would not know...had it not been for tragedies and for bad things that happen. And, you know,...we're happy that we became friends. I have a lot of friends [who are] bereaved parents, but we wouldn't have known each other [otherwise] most likely. (pg 57, lines 19-23)

Although supportive, friendships with bereaved parents can be both comforting and difficult. Doris explains, “I do get a lot of comfort from girlfriends who have been there, done that...that’s a good thing and even then it’s hard because...they don’t want to offend me [and] I don’t want to burden somebody else” (pg 101, lines 12-17).

Friendships with non-bereaved parents are appreciated as well. Emma enjoys her friendships in her Church Senior’s group with whom she meets for monthly ‘dinner-and-a-movie’ gathering (pg 81, lines 10-13, 15-19). One of Emma’s non-bereaved friends will join most of their get-togethers throughout the year except their Christmas dinner (pg 61, lines 16-22; pg 62, line 1). Emma explains:

She will do anything with us through the year. I invited her the last three times and she will not come to the Christmas thing. She said that is our time together and she won’t because she’s never lost a child. But she’ll do the other things with us, but not the Christmas thing. I guess...she thinks we should...do it with each other. (pg 60, line 22-22)

Although welcomed, friendships with non-bereaved parents do not offer parents the same level of support. Emma says, “friends that had never lost a child, they couldn’t understand it” (pg 61, lines 8-9). Peter’s non-bereaved friends have not been a substantive source of ongoing support. Rather, Peter feels isolated from his friends and feels his former circle of friends is like a club that he doesn’t fit into anymore (pg 47, lines 12- 23). Peter describes what it’s like not to fit in with his friends, explaining it is like “when you get a divorce and you really, really, really loved your sister-in-law and talking to her, but you can’t now and that’s because what connected you is no

longer there” (pg 47, lines 15-17). Peter wonders, “Is this going to change?” (pg 48, line 2).

What parents need in terms of support. Parents need many things in terms of support. Parents need empathetic reassurance. Doris explains, “Sometimes I just want somebody to say ‘You are alright. It’s ok that you feel so sad and you loved her’” (pg 89, lines 17-18). Parents need realistic encouragement to persevere. Doris says, “other days I need somebody to say ‘you need to suck it up a little bit and do this’” (pg 89, lines 18-19). Although Doris needs encouragement, she says “I don’t want a cheerleader...I want somebody who’s realistic about it and says, ‘Yeah, you can do it and this is what I know and this is how you get through it’ by writings or whatever” (pg 118, lines 7-11). Parents need to talk about their experience. Doris prefers to communicate verbally, rather than texting or emailing which can lead to misunderstandings. Doris explains:

[Texting and emailing is] almost my license to be a jerk about things. I say things...and then I feel bad because I said them. The filter I once had, I don’t use as much. I feel like talking helps keep me more comfortable too as opposed to just [texting or emailing]... when you can’t see my face or hear my voice, you don’t know that I’m saying it because I’m having a bad day. (pg 101, lines 2-7)

Emma says, “just talking about her helps me” (pg 8, line 14). The reason talking helps is because, as Emma says, “you want people to know that she did exist and she was and is *still* [emphasis added] my daughter” (pg 14, lines 11-13). Talking also helps Emma remember Dorothy (pg 16, line 7). Parents need people to take the initiative in

offering her support, rather than leaving it up to them to reach out to others when they are feeling the need for support. Doris explains:

There are sometimes when I just want ...people to know just how bad it sucks, how bad it hurts...but yet, I don't have the strength to, I just can't pick up the phone. I just want people to know that it's a bad day on October 25th, 2012. (pg 102, lines 1-4).

Parents need people to understand and to be present. Doris shares the following story to illustrate how much she needs people to understand and maintain a supportive presence:

I wanted my sister and a girlfriend...I asked them both to go with me. I spoke at a [childhood cancer awareness] event and I wanted them to go with me and the reasons they couldn't go, in my head, were pretty lame ...if you could just understand how hard it is, that I just need somebody there who knows me, who loves me, who will...kinda stand beside there for me. I'll do the speaking, you just need to kinda support and neither one could make it a priority...it hurts that there's such an inability to understand how hard, how much your life is changed, how...the ache of her loss is just constant...I guess there's just no way for anybody to understand it...sometimes I think it really is me as much as anything. I expect people to know things when I can't say it out loud. I can't. I'm having bad day. I haven't responded to your phone calls or text messages. I just need you to stop over. And in your busy life and whatnot you just think I haven't responded because I've been busy....It's like I almost expect people to know and they don't get it because they don't get it. (pg 123, lines 13-22; pg 124, lines 9-15)

If more people understood what life has been like for Doris since Cindy's death, Doris says "it would help...it absolutely would" (pg 124, lines 19-21). If more people understood the reality of parental bereavement, Doris would not be left to experience it all alone. Doris says:

I feel very, very much not understood...not understood...I don't want anybody to do this. I don't want anybody to do this! But, I don't know why, but sometimes I'd like a little bit of if everybody could have a little bit more

insight. I don't want anybody to suffer. I don't want anybody to lose their child. A little insight from time to time I think it would be good. It would be less lonely. (pg 109, lines 17-23)

Parents need support from anything that helps them feel better. Emma explains:

That's the thing I would advise any [parent]...[try] anything that is out there, just grab a hold of it and don't [let go]...I try to do things that I know will make me feel better...some people I think don't want to try new things and I would advise them to do it. Because sometimes you can find out that it helps you so much and you've made new friends. So I think you really have to. That's the way I feel anyway. At first you feel overwhelmed by it, but as you work through it [you realize] you can't do it alone...you have to reach out and unfortunately for me there was nothing to reach out to for so many years but that's one thing I would advise for people to try it. (pg 81, lines 19-23; pg 82, lines 9-15)

Regardless of one's background, occupation, or life experience, all parents need support after a child's death. Sara says that losing a child is "hard no matter who you are" (pg 8, line 18). Sara recalls how people often made incorrect assumptions that she did not need support because she often provided support to others in her role as a pastor's wife. For example, Sara recalls receiving a follow-up phone call from the hospital after Adam died. Upon the realization of Sara being a pastor's wife, the hospital staff member stated, 'Oh, you're OK then' (pg 9, line 2). The hospital staff member erroneously assumed that since Sara often provided bereavement support to others, she was not in need of support herself. Reflecting back to that time, Sara feels she was "struggling with depression" (pg 15, line 14-15), but felt unable to discuss this with anyone because of imposed expectations and assumptions of what she as a pastor's wife should be (pg 15, line 15-16). The hospital staff member's lack of

understanding about the parental bereavement experience left Sara feeling further isolated and alone.

Support is necessary not only immediately after a child's death but also for the duration of a parent's life. Many of the parents felt supported within the first year following their child's death. Family and friends' provision of specific acts such as providing meals, helping with household chores, doing necessary errands, and listening were the most helpful types of informal support. Parents also received formal support from established bereavement support groups. While most received informal and formal support soon after their child's death, this was not the case for all parents. Emma, for example, had neither informal nor formal support for many years. The complete, utter lack of support intensified Emma's suffering, specifically the isolated feeling of being alone. Emma explains:

When it happened to me, there was nothing. There was nothing to go to for grief...it was a different world...I had no one to lean on or no one to help me...there was no Compassionate Friends...now they have all those things...for the parents...[but] back then it was horrible. (pg 20, lines 18-19, 21; pg 54, lines 16, 19, 21-22)

When formal support eventually became available 25 years later, Emma was finally able to grieve openly in the presence of supportive people. Emma states:

They told me when I went in there that it was like I was newly bereaved because I hadn't been allowed to grieve...that was good that I...got there, even though it was a lot of years later. It really was good. (pg 6, lines 2-3, 5-6)

It is clearly apparent that all parents need support immediately following a child's death.

While others may recognize parents' need for support immediately following a child's death, they often do not understand parents' need for continued support beyond the first bereavement year. Unlike everyone else who carries on with their lives, parents live with the loss of their child every day for the rest of their lives. Sara articulates this fundamental difference in the way she and others experience Adam's death:

The difference there is that while we are living the reality of it every moment of every day, others have the freedom to walk in and out of our lives--to take a break, to forget.... We don't have...that freedom. (Sara, personal communication, CaringBridge® journal entry, April 14, 2010, pg 29, lines 8-10)

Doris adds:

Their life has gone on and they're ok, so they [think] I must be feeling better. I should be feeling better and they don't have to be here for me anymore, or support [me]...because clearly it's been enough time that I should be better....I don't know that people judge or feel that way, but that's how it feels when you're lonely and sad and you try to reach out to somebody and they just totally miss the mark, totally don't get it...maybe they could have rearranged something and come over and sit with me, or be my friend, or do this with me...I feel people should stick by you in your time of need. I don't know, maybe the rest of your life is just too long. (pg 101, lines 11-12; pg 123, lines 3-6, 8-12)

Parental bereavement is a lived experience that has no end point. In fact, the second bereavement year and beyond can be just as difficult as the first. Doris finds no difference between her first and second bereavement year. Doris explains:

I can't believe that it has been two years since she died and yet it feels like it still was yesterday...that's the part that just doesn't make sense to me. How two years goes by and that's a long time and I don't feel that *different* [emphasis added]! I still wake up and expect to hear her voice some days...it's

been two years but it doesn't feel like it's been two years. (pg 71, lines 15-17, 19-23; pg 72, lines 1-2)

Sara finds that her third bereavement year is no better or worse than the first or second year and explains, "this is what it is going to be like for the rest of our lives...I don't think it's something you get over" (pg 92, lines, 2-3, 19).

Joan and Emma have found that their 15th and 41st bereavement years, respectively, are somewhat different than their earlier bereavement years because their grief is less intense. However, because grief still intensifies in the face of situational triggers, this aspect of bereavement remains unchanged. Joan explains:

I think [grief has] changed. Occasionally, I find myself back to, not the first day of course when he died, but ...I find myself [back] to an earlier time in my bereavement, going back to those moments... I do find myself feeling like those early bereavement moments when I'm overcome with either sadness or longing for him. (pg 45, lines 18-20; pg 46, lines 7-10)

Emma's grief also continues to be part of her parental bereavement experience.

Emma states, "You would think that after all these years [grief] would have lessened, but it hasn't. Sometimes, it's just still unbelievable" (pg 5, lines 4-6). Consequently, parents need continued support. Unfortunately, most parents have found that the amount of support decreases after the first bereavement year. Decreased support intensifies parents' suffering and, thus, impedes their journey towards healing. Kelly explains what it is has been like for her since the informal support once provided by Sam's school nurse, teachers, and her friends vanished 1.5 years into her parental bereavement experience:

We are very alone. People have disappeared. People are not around. They don't call anymore...there are people who left us when we need them. I'm at that point now...that I'm thinking about that...Now that I need you, you are not there. So I'm feeling that now...they were all there and it's very overwhelming. Now, to have very good friends [infer] "ok, we're back to normal". No, we're not! Nothing is going to be normal again. It's not. So...a phone call might still be nice. Out of the blue,...'Hey, whatcha doing', you know? And it's difficult and that's where I'm at right now with a little attitude, slight. But I also understand that people, you have your own life to deal with but be in my shoes for a little while... Be in Jeremy's mom's shoes. See how we're feeling. Yeah, I'm sure you'll be a little angry. (pg 34, lines 6-17; pg 85, lines 1-2)

Kelly provides an example that clearly illustrates the profound sense of abandonment she feels as a direct result of the disappearance of informal support. Kelly explains what happened at the hospital's annual marathon fundraiser:

Last year, we had such a large crowd. This year, there was a handful. I mean...we counted them. It was awful. And I know you don't have to...force people to come and do something, but when people say that they're going to come and they don't. So that happened. So people who I expected to be there for Sam were not, including the nurse...including all of Sam's teachers. It was a letdown to be honest...It's a wonderful event, a wonderful event...but no one came... I can't make people come, you know? It just seemed so different from last year. And you kind of expect that... [but it] makes me [think,] 'It's ok Sam, maybe they were just busy' and you...once again go back to that guilt factor...'They won't forget you I promise'. (pg 50, lines 11-17; pg 51, lines 1, 3, 5-9)

Not only was Kelly left feeling abandoned, her greatest fear was realized: people are forgetting Sam in spite of her best efforts to keep his memory alive (pg 77, lines 21-22; pg 88, lines 21-22; pg 99, lines 2-4; pg 103, line 21). Doris also expresses a sense of abandonment 2.5 years into bereavement caused by the disappearance of informal support. Doris explains:

Even those who were here for us right after Cindy passed, your closest friends,... even people who really stuck around the first 18 months with us...people just don't call anymore...there's very little friend relationship anymore. Very, very few, we just don't have much...of a...social peer group...left...I don't feel like I have anyone to really talk to about it. (pg 88, lines 10-11, 20-23; pg 89, lines 1-2; pg 100, lines 8-9)

Parents struggle to identify the reason why people wander away leaving them without the informal support they so desperately want and need. Parents wonder if supportive people disappear because they forget, they don't care, or they simply don't understand parents' need for continued support. Often, parents blame themselves. For example, parents wonder if their grief drives people away and impedes their ability to be a good friend. For example, Doris states:

I know I need active friendships. I just don't...have the where-with-all to be a good friend. You have to be one to have one and I think people like me don't have the strength to be good friends. Maybe that's why the support group dwindles because...I'm just too tired and so where I would care before, I kinda care, but not enough to do anything about it...I can ramp it up when I have to, but I find that my endurance over the long haul isn't as good...and then...I just curl back up in my cocoon...I'm just done. I'm drained. I've got nothing left. I feel...I can do it, I can do it, I can do it for so long and then I just can't do it anymore. (pg 103, lines 5-10; pg 104, lines 2-3, 5-6, 10-12)

Parents may also question if they are being oversensitive and selfish. Kelly ponders:

Am I being oversensitive? It's like I'm always questioning myself. Should they have been there? Yeah, I think if they were two friends being supportive, then yeah they should have been there. Do I have a right to be mad? I don't know...I don't know if that's within me, or whether I'm being selfish and not thinking about other people's lives and they've got to continue their own life. (pg 52, lines 10-15; pg 87, lines 17-21)

These are examples of the types of questions parents wrestle with when support disappears. The answers are not fully clear; however, what is clear is that it is parents'

perception that people disappear because they are forgetting, which in turn intensifies grief feelings including guilt, fear, self-doubt, anger, loneliness, and feeling abandoned. The convergence of guilt, fear, self-doubt, anger, loneliness, and feeling abandoned that are generated when once-supportive people disappear add considerably to parents' suffering and impede their arduous journey towards healing.

Things People Say or Do Minimize Additional Suffering

What people say to or do for parents can be comforting after the death of a child and thereby, minimize additional suffering in parental bereavement. Most parents describe situations in which people have said or done certain things that provide some comfort. When a parent is comforted, grief lessens for that moment in time or when they recall that situation at a later date. These situations fall into the following three main categories: a) when people listen to and talk with parents; b) when people carry out acts of kindness; and c) when people acknowledge and include parents.

When people listen to and talk with parents. When people listen to and talk with parents about their child, it minimizes distress and prevents further suffering. Listening and talking with parents help them feel less isolated and more supported. Parents need people to listen to them talk about their child. During Kelly's interview, she shared a written expression of her parental bereavement experience in the form of a letter that she wrote to Sam. In this letter, Kelly articulates her need to have people listen. Kelly writes, "Some people have reached out to help me, others have turned

away unable to hear the pain I carry. I do not ask them to share it with me, only to listen as I talk and cry” (Kelly, personal communication, May 24, 2012, lines 10-11). Kelly tells of one instance when she was comforted by the simple act of distant family members who listened to her talk as they sat together watching videos of Sam (pg 110, lines 11-14; pg 111, lines 4-7). Kelly was very appreciative of this.

Like Kelly, Joan also found some people who were willing to listen. Joan kept a list of these people so she would know who she could call if she wanted to talk about Joshua. Joan explains:

Not one person could be everything to me, so I had three or four different lists...I had a list of people who, if I wanted to talk about Joshua, I could call those people. And I mean really, they wanted to talk about him. And then there were people who I knew if I called, they would not want to talk about him. So if I didn't want to talk about him, I could call those people because there was *no way* [emphasis added] they were bringing up his name. (pg 53, lines 11-17)

Doris also appreciates when people listen to her talk about Cindy and says, “it feels good to have somebody listen” (pg 50, lines 20, 22). Sara suggests helpful things people can say to a bereaved parent that convey support and caring. Sara advises:

Just say I'm sorry. Just say you are thinking about me. Just tell me what you remember about Adam. Just tell me what you loved about him. Just tell me that you think about him, or that you pray for us,...[or] I want you to know that I really care' ... just support, just kindness, just caring. (pg 33, lines 5-7; pg 34, lines 3-4)

Listening and talking helps parents remember, helps parents continue their relationship with their child, and helps parents to know that people have not forgotten

their child. Talking helps bereaved parents remember their child. Emma says, “just talking about her helps me” (pg 8, line 14). Emma says:

The thinking is, ‘Don’t bring it up because it will make her sad’. But, the sad thing is...it’s always on your mind. They’re not reminding you of anything that you don’t already know in your mind... she’s my daughter. I *want* [emphasis added] to remember! (pg 16, lines 2-7)

Talking is important because it also helps bereaved parents continue the relationship they have with their child. Emma says she, like other bereaved parents, “want people to realize they were and...they *are* [emphasis added] a person. You just don’t cut it off after they *die* [emphasis added]!” (pg 72, lines 1-3). Doris wishes more people would talk about Cindy with her. For example, Doris would like it if people made comments such as, ‘Cindy would have really liked that’ or ‘What kind of dress do you think Cindy would have worn?’ because these are things Doris herself thinks about in her continued relationship with Cindy (pg 93, lines 12-14).

Talking also helps parents to know their child has not been forgotten. Emma says:

I just wish that people would have [talked about her]. It was like they liked wanted to pretend she never existed...you want people to know that she did exist and she was and *is still* [emphasis added] my daughter...I always say that...if they just...let you talk and if they just let you know that they are there for you and that they know that your child was a person...the little things can really help a lot. At least to me they would have... even now today it means so much. (pg 14, lines 10-13; pg 20, line 23; pg 21, lines 1-4)

For example, it helps when Emma’s daughter-in law talks about Dorothy, about which Emma says:

She always, always asked me *something* [emphasis added] about Dorothy! She would ask me a question about her and I would tell her.... I told her how much it meant to me... I said, 'Whenever I've been in your company lately, you always...talk about Dorothy with me...you don't know how much that means to me!' ...she thanked me....I feel like I just wanted her to know that it did mean something to me. So, it's like the little things [help] if people could only realize. (pg 19, lines 17-19, 21-23; pg 20, lines 1-3)

When talking with a bereaved parent, it is very helpful to say the child's name aloud. Joan tells the story of when she had first met a woman who happened to already know about Joshua's death, the woman expressed her condolences to Joan and commented how nice a boy Joshua must have been (pg 57, lines 10-21). About this Joan says:

That was so *nice* [emphasis added] of her to say his name and to acknowledge that he did live and it was priceless just to say that to me. I think people don't want to say his name to me. Do they think I'm not thinking about him? Do they think I just don't want to ever mention him again?...she didn't think I was going to crumble, or die, if by saying it...she was very appropriate and she was just very brief and it was done. I could have hugged her for it and it was, '*Ah, oh my God, someone said his name* [emphasis added]! I'm so happy the day before Mother's Day [because] they remembered him'. (pg 57, lines 17-21; pg 58, lines 8-11)

Joan took great comfort in that moment and does to this very day, saying "it was just perfect...such a gift" (pg 58, lines 15, 17).

It also helps Emma to hear Dorothy's name said aloud. Emma attends an annual memorial service every December during which Dorothy's name is read aloud. Emma says:

One of the things in the memorial service that is read every year, it's called,...'Say Their Names'...it's a beautiful, beautiful thing they read. It tells people that we want to hear their names. We want people to realize they were and...they *are* [emphasis added] a person" (pg 71, lines 21-23; pg 72, lines 1-2)

Hackett's (1986) poem, "Say Their Names" (Appendix C), written after the death of his own son, reflects parents' experience.

When people carry out acts of kindness. When people carry out acts of kindness, parents are comforted and feel supported. Doris says, "kind, sweet, unexpected gestures... bring so much relief, even if its temporary" (pg 124, lines 22-23). Parents describe various acts of kindness that have brought them some comfort. Kelly expresses appreciation of her neighbor who, recognizing how difficult Mother's Day was going to be for Kelly, brought her a plant and a 'thinking of you' card (pg 54, lines 5-8). Peter appreciates the acts of kindness that people have done for him, including shoveling snow, raking leaves, and paying for gas (pg 18, lines 4-5, 14-16). Peter says, "I appreciate that, but I would so trade that for in a second. I am very fortunate. There are other people who go through the exact same thing and nobody...offers them a dinner or [pays their] gas bill" (pg 18, lines 9, 12-14). People did similar acts of kindness for Joan, including preparing meals, doing household chores, or running errands (pg 53, lines 17-19; pg 60, lines 14-23; pg 61, lines 1-5).

Some parents describe acts of kindness specifically done in the child's name. For example, Doris explains how Cindy's elementary school teachers created an award in Cindy's name that is given to a child who embodies her spirit of being willing to help others (pg 65, lines 20-23). Emma also describes being comforted when her grandson named his baby after Dorothy. The fact that her grandson wanted to name his daughter after Dorothy eases Emma's grief. Emma says:

That keeps me being happy...thinking about this baby overwhelms me. I can't wait...I never had a sister to confide in or anything... my only daughter is gone. I never had a granddaughter. So, I think the good Lord took pity on me and he's giving me a great-granddaughter. I'm looking forward to that. (pg 70, lines 20-21; pg 73, lines 17-20)

In a letter Emma sent me one week after the baby's birth, she writes:

On Feb 7th we had the addition of my great-granddaughter to our family. We are all just so happy! I prayed it would be a girl. Her name is Anna Dorothy. How about that! I have held her so many times and feel so blessed. She smiled for me the other day. How great is that? (Emma, personal communication, February 18, 2013)

Doris describes a kind act of remembrance that she received from a friend,

who is a teacher:

She did it she did it so perfectly. They made these little butterflies and...they put names, they could write a thought, a word...that they...thought of when they thought of a friend who might be sick or something. I don't know how she arranged it but...she did a little mini fundraising activity and she took their picture and...she took these little butterflies and on her way home from work she stopped at our house and put these butterflies on my porch so that when I got home that day, there was a note from Mrs. Martin's kindergarten class saying how much they loved sharing about Cindy. (pg 125, lines 1-18)

Doris explains just how much this kind act means to her:

Those little things mean a lot!...it feels so special that somebody is willing to do that...it's always interesting to me that its people that I least expect, or least close to us, or were not necessarily part of everyday life, you know not a part of the fight after she was diagnosed. There are so many good and sweet people out there. (pg 125, line 20; pg 126, lines 7-11)

When people acknowledge and include parents. When people acknowledge parents' experience and include them in activities that they feel comfortable doing, parents feel less isolated and more understood. Being around friends and family decreases a bereaved parent's sense of isolation. For example, Doris explains how

much it has helped that Cindy's best friend's parents have included her in their child's life. Doris says:

Her parents have given me the greatest gift of all, which is to let me be part of her adolescent growing up world as I can be...they are very generous...I did all her eighth grade dance shopping with them. I seriously ordered 12 dresses for the eighth grade dance last year and we had a mini dance experience in the home and then I returned all but one. They are very good about letting me be her other mother, so to speak, and that's nice because once and a while I come in handy...they really are generous because they really are accepting of letting me be her, sort of adopted mother...I've gotten to do a lot of things that I wouldn't have done if I didn't have Mary. That is for sure. (pg 97, lines 9-19)

The fact that Doris was included in these activities that she felt comfortable with minimized the feeling of loneliness.

Emma also feels less lonely when she is around friends and family. Emma says:

My doctor told me she'd never known anybody to have as many friends as I do, but...that helps...seeing different friends and...doing things, even though, other than my Compassionate Friends, they...haven't been through this. I think the more friends you have...that helps. (pg 23, lines 10-15)

Emma is not only thankful for her friends (pg 65, lines 17-19), but also for her nephew's family and her grandson's family who include her in their birthday and holiday celebrations (pg 65, lines 1-7, 17-19; pg 72, lines 17-23; pg 73, lines 1-13).

Emma says, "I just really look forward to...[being together]" (pg 73, lines 11-14).

When people acknowledge parents' experience, parents feel more understood.

Emma's dear friend always acknowledges the fact that Emma is Dorothy's mother.

This is important to Emma. Emma explains:

Even today [when] she emails me or mails me anything, she always puts it to ‘Dorothy’s mommy’ and that *means so much* [emphasis added]! I open an email, or anything, and she has that on there...it’s just a little thing, but it means so much to me. (pg 22, lines 2-6)

Her friend’s acknowledgement that Emma will forever be Dorothy’s mother helps Emma to feel more understood.

In summary, people’s words and actions can give bereaved parents comfort and thereby, minimize suffering in parental bereavement. Emma states, “I would hope that any parent today that goes through that horrible thing that there would be people there that would try to understand and try to be helpful to them. I really do pray” (pg 27, lines 11-13). Opportunity for education exists. Specifically, educating people about what to say or do for a bereaved parent may prevent additional distress and further suffering. If people’s words and actions of comfort were maximized, additional suffering in parental bereavement could be minimized. People need to understand that their words and actions can have a positive impact on the parental bereavement experience.

Health care Providers’ Behaviors and Care Processes Minimize Additional Suffering

Bereaved parents remember the care that they and their child received during their child’s illness. Recollection of care encounters that bring comfort minimizes additional distress after a child’s death. When a parent is comforted, suffering lessens. Most parents describe comforting care encounters. Hallmarks of comforting care

encounters include caring behaviors, continuity of care, partnering in decision-making, maintaining presence, and acts of kindness.

Caring behaviors. Caring behaviors, such as maintaining presence and attending to child and parent needs during hospitalization, minimize distress and offer a source of comfort after a child's death. Most parents recall caring encounters when health care providers demonstrated caring behaviors. Upon remembering these encounters, bereaved parents are comforted.

Forty one years after Dorothy's death, Emma is comforted by the genuine care of Dorothy's physician. Emma vividly recalls one example that illustrates the physician's caring behavior of maintaining presence. Emma says:

He went over and I was sitting besides [*sic*] her bed and he stood. He was a tall man. He had a mustache and he stood and he rubbed her arm and rubbed her arm and...he just...stayed for a little while rubbing her arm...my mother-in-law had been in the room. He was over by the window. I couldn't see his face, but she could and she said she thought he was going to eat his mustache he tried so hard...not to cry. So he was a wonderful, wonderful man and I know that...he had feelings and he had...taken care of her so long and I know it meant something. (pg 10, lines 20-23; pg 11, lines 1-3, 5-7)

Kelly expresses appreciation and a sense of comfort when recalling team members' attentiveness to her family's needs, including: a) Sam's case worker, who was "always there if we needed her" (pg 12, line 9) especially when coordinating Sam's care in the hospital and when coordinating Sam's funeral services (pg 21, lines 18-23; pg 22, line 1); b) the nursing staff, who provided comfort measures and treated Sam "like a prince...he loved the ice packs...he would have his feet rubbed every day with the cream...he was treated well, like a prince" (pg 73, lines 1-3, 5); c) the child

life specialists, who would always make sure that Sam could play during hospitalizations and “always had plenty to do” (pg 13, lines 6-8, 10-12); d) the Ronald McDonald House staff who offered Kelly’s family a place to stay, personal toiletries, and clean clothes (pg 21, lines 9-16); and e) the hospital food staff, who attended to Kelly’s basic needs by bringing her extra food and beverages without her having to ask (pg 15, lines 9-10, 12-15, 17). Kelly says they “were the best people on this earth...I wouldn’t change them with a penny, wouldn’t change them with a penny” (pg 15, lines 9-10, 14-15).

Joan takes comfort in remembering helpful things that nurses did for Joshua during his illness, such as being supportive when accessing his port-a-cath to obtain a blood sample. Joan explains, “the nurses...were just great...for the most part...emotionally, they were very supportive” (pg 40, lines 1-3).

With loving affection and respect (pg 17, lines 14-15; pg 51, lines 1-4), Doris also recalls how Cindy’s nurses attended to her needs, such as offering the caring gesture of a hug (pg 46, lines 6-10), skillfully administering medications (pg 46, lines 12-16, 18-19, 21-22), walking to pharmacy to personally pick up Cindy’s pain medications to avoid unnecessary delay (pg 53, lines 5, 7-10), maintaining hope (pg 47, lines 15-17), and making her feel safe (pg 17, lines 13-16, 18-20, 22; pg 127, line 5). Doris recalls one situation in particular when the outpatient nurse and nurse practitioner gently escorted Cindy out of the room so the pediatric oncologist could first communicate the news of Cindy’s diagnosis privately with Doris and Roger (pg

17, lines 13, 22). Doris says, “I couldn’t love them more in the world...those two women...as far as I’m concerned, are almost God. They...made the most miserable, awful point in Cindy’s life...at least... acceptable...Cindy always felt safe” (pg 17, lines 15, 18-20).

In addition to meeting Cindy’s needs, Doris also needed nurses to listen and attend to her own needs. For example, Doris appreciated the inpatient nurses granting her request to have Cindy remain in her room for a peripherally inserted central catheter (PICC) insertion procedure (pg 44, lines 18-23; pg 45, line 2) and teaching her how to bathe Cindy (pg 45, lines 4-9, 11, 13). Doris says, “to be in a situation where you feel heard, like you have some opportunity to help your kid...that was really important to me” (pg 45, lines 2-4). Doris also remembers the gentleness and kindness of the nurses on the night of Cindy’s death, including the sensitive manner in which they communicated the news of Cindy’s death (pg 53, lines 12-14) and the way they braided her hair to make her look pretty (pg 54, lines 6-12). Doris says, “I am still really grateful that they were there because...number one, they had loved Cindy the entire time we were there and...two...they had loved us...they were just really great” (pg 54, lines 9-12).

Doris stresses the importance of nurses caring for both her and Cindy (pg 47, lines 7, 10-13) and shares the following sentiment:

My nurses were so much more important than my actual doctors at that point. Actually, really, being honest the whole time, once I got the diagnosis from the doctor and they come and all that, but it’s your nurses who provide all that...ongoing care. (pg 45, lines 20-23; pg 46, line 1)

The sense of relief and comfort that comes with knowing that nurses attended to her daughter's needs, as well as her own, remains with Doris 2.5 years after Cindy's death.

Doris also recalls how sensitively and respectfully Cindy's pediatric oncologist communicated the news of her diagnosis, specifically having the conversation in a small, sunlit room (pg 17, lines 9, 23) where they were both seated (pg 18, lines 2-3) and using clear, simple yet sensitive words: 'Cindy has diffuse intrinsic pontine glioma...this is absolutely the worst diagnosis I can give a parent' (pg 18, lines 10-12).

Doris says:

Those are the words that I remember...he didn't say it for effect and he was apologizing while he was doing it. It wasn't like... 'I'm looking for a reaction here as I tell you'...It wasn't that at all. It wasn't for over-effect. It wasn't drama. I just think it was maybe to help us grasp...what we were facing. (pg 18, lines 16-17, 19-23)

Continuity of care. Continuity of care during illness is a source of some comfort for parents after a child's death. Continuity of care is a key aspect of primary nursing, which parents find helpful. Joan explains, "they gave us the same nurses all the time...they were familiar with him, they were familiar with me, he knew them, so he was [cared for] by people he felt comfortable with...that was very helpful, very helpful" (pg 40, lines 4-7, 8).

Doris also found the continuity of primary nursing to be helpful because she was able to develop relationships with the nurses who cared for her daughter (pg 42, lines 8-21; pg 43, lines 1, 3-6, 17-19; pg 44, lines 1, 5-7). Doris says:

For me, it was great to be able to develop a relationship with some of those nurses and know what it would be like to know when that person was on...we kind of knew what to expect from each other and that was really helpful on her last days. (pg 42, lines 14-16; pg 43, lines 18-19)

Positive memories such as these still remain a comfort to Doris more than two years after Cindy's death. A comforting memory such as this minimizes additional distress in parental bereavement.

Physician continuity was also helpful for Doris. When Cindy's tumor bled, Doris was fearful that new physicians would order Ativan®, a medication Doris' mother is highly allergic to (pg 38, lines 14-15, 17-23). Doris explains how one physician who closely cared for Cindy throughout her illness finally arrived to pediatric unit (pg 39, lines 1-4, 6-7), acknowledged Doris's fears (pg 39, line 10), and explained how this medication would help Cindy be more comfortable (pg 39, line 9-11). Doris says:

I was so excited to see him because he was somebody I felt knew her, knew us, and he was able to calm me down... he gave me the control I needed back...because that's the thing when you're dying, there is no control. (pg 39, lines 8-9, 11-12)

Partnering in decision-making. Health care providers who partner with parents in decision-making can minimize additional distress after a child's death because parents find solace knowing that they were respected and valued. For example, after Kelly and her husband consented to Sam's DNR order, the doctors and nurses listened to their request to check Sam's blood work so they might gain a better sense of his current status even though they knew he was actively dying (pg 10, lines

6-10, 12-13). When Kelly remembers this encounter, she expresses a sense of relief rather than distress because what she wanted for her child was respected.

Maintaining presence. Health care providers who maintain a supportive, caring presence after the death of a child minimizes additional distress in parental bereavement. Kelly's distress is minimized when Sam's health care providers connect with her. For example, Sam's surgeon periodically contacts Kelly to see how she is doing (pg 67, lines 11-13; pg 118, lines 5, 8). Kelly describes just how helpful it's been to have the surgeon stay connected with her: "very much so...the surgeon, *holy smokes* [emphasis added]! I mean, we're like this [crosses fingers] but that's how much faith you put into your teams" (pg 67, lines 11-13). Kelly likes to stay in contact with Sam's nurses with whom she developed strong relationships and will initiate contact with them on Facebook or when visiting friends in the hospital (pg 118, line 1-2, 9, 11-13, 15-16, 18-21). Kelly states:

The nurses at the hospital...I love them to bits and I know they are dealing with other children so...they help Sam to a certain point and then that was it...they get very sad and they have to [distance themselves]. But, I'm still in touch with them...they don't forget. That's still important to me...'cause they're the ones who looked after my Sam" (pg 117, lines 20-23; pg 118, lines 1-2, 4-5)

An ongoing relationship with her child's health care providers is also important to Doris. Doris expresses a need to maintain a relationship with the nurses because they are her connection to Cindy. Doris explains:

There is such a desire on the part of me as a mom...to remain a part of their lives even though I am not. I know that sounds really strange but...they are my last connection to Cindy. They were the ones, at least at the time, that loved her like I loved her or we're gentle with her...they make you feel connected to

your child as the last people who helped me bathe her and do her hair and make her feel safe and comfortable...so I think it's a very important thing. (pg 44, lines 10-16; pg 127, lines 4-6, 8)

While Doris doesn't feel as connected with the nurses as she did immediately after Cindy's death (pg 126, lines 16-17), Facebook provides a forum for their connection, whether it's the nurses responding to posted pictures of Cindy (pg 128, lines 2-3) or Doris following events in the nurses lives such as going to school (pg 127, lines 14-18), getting married (pg 127, line 20), or having babies (pg 127, line 20). As much as Doris wants more of an ongoing relationship (pg 127, line 13), she feels "it's a healthy connection" (pg 127, line 12) and understands how hard it would be for nurses to do more because of the effects that caring for a vast number of sick, dying children would have on them personally (pg 44, lines 9-10; pg 127, lines 8-14). Doris says:

I think it would be very hard to be on their end of it and so I understand the reluctance...[they] just can't befriend the parent of every child on a heme-onc ward for crying out loud...they lose kids daily practically. (pg 127, lines 8-11)

Staying connected to Cindy's oncologist is important to Doris (pg 128, lines 2-7, 13-22). Their communication has tapered off from once every several weeks to once every few months (pg 128, lines 5-7). Doris usually initiates email communication, to which he promptly replies (pg 128, lines 19-22; pg 129, line 1). Doris appreciated receiving an email from him that said, "Let's talk soon. Give me a call" (pg 129, lines 2-3); however, Doris says, "that's easier said than done" (pg 129, line 5).

A parent's own health care provider who maintains a supportive, caring presence can be a comfort. For example, Emma's therapist has maintained a

supportive presence. On their first meeting, Emma says the therapist told her “I’ll never leave you” (pg 25, lines 3-4) and she meant it. The therapist didn’t even abandon Emma when she lost insurance coverage. Emma explains what happened:

They dropped my insurance when I got cancer and so I had to get another one and then in the meantime...there was a mix-up...they wouldn’t pay for my visit. So [my therapist] said ‘I’m not leaving you...I know you won’t come if you don’t pay something...how about \$5?’. And I said, ‘oh my goodness’. She said, ‘no that’s it’ and so every time that I went I gave her a check for \$5. Well, after a while... [the insurance company] went back and gave her all the weeks that they hadn’t. And she gave me all of my money back that I had paid her...it was like over \$100...she gave me that back...I have never known a doctor to do that before, but she didn’t want to lose me....she’s just always been so wonderful I’ve never known a doctor like that... the good Lord had a hand in picking her out....I have been going to her so long now and she said she is never going to leave me” (pg 25, lines 5-9, 11-17, 19, 21-23; pg 76, line 23; pg 77, lines 3-4, 18-19)

Acts of kindness. Health care providers who are not directly involved in either the child’s or parent’s care, but who interface with the parent indirectly can offer comfort by committing acts of kindness. Emma provides an example. When Emma telephoned her brother at the hospital the night her nephew was killed, rather than saying ‘call back’ or ‘I’ll have him call you’, the nurse simply allowed Emma to stay on the line until he could answer (pg 26, lines 8-19, 23; pg 27, lines 2-3, 5).

Emma says:

The good Lord has good people at the right time...I called and the nurse said that the priest was in with them and she said, ‘Whenever they get finished, I’ll get your brother on the phone...just hold on’ and she let me hold on that phone. I don’t know how long it was until she went...and got my brother and I talked to him. I’ve often thought about that....that was an extra kind act from her...So,...along the way it’s been hard and it’s been lonesome and it’s been horrible, but the people that have gone that extra step, I think that’s what has helped me a lot...I thought that was so nice. (pg 26, line 9, 12-19; pg 27, line 5)

In this simple, yet powerful example, Emma gives testimony to the long-lasting, positive impact nurses have not only on immediate family members currently under their care, but also on an extended family member's lived experience of parental bereavement experience. I wonder if this nurse realizes how helpful she was to Emma and her brother on that particular night and remains so today, 27 years later. Emma says, "I would hope that any parent today that goes through that horrible thing that there would be people there that would try to understand and try to be helpful to them. I really do pray" (pg 27, lines 11-13).

The finding that health care providers' behaviors and care processes minimize suffering in parental bereavement is compelling and advances knowledge in the field. It is recognized that health care providers' attempts to include parents as partners in decision-making and caregiver continuity during a child's illness (Contro *et al.*, 2002), as well as compassionate caregivers who maintain presence and strive to continue a relationship with parents after a child's death (Contro *et al.*, 2002; Macdonald *et al.*, 2005) are appreciated by bereaved parents. This study builds upon this foundational knowledge. Caring behaviors, continuity of care, partnering in decision-making, maintaining presence, and acts of kindness are not only appreciated by bereaved parents but most importantly minimize additional suffering after the death of a child.

Meaning

Along the journey towards healing, bereaved parents search for meaning as they try to make sense of why their child died and find a new life purpose. Their

search leads them to activities that have great meaning. Parents in this study have become actively involved in diverse, meaningful activities. Many parents are actively involved in various aspects of the childhood cancer community. Parents participate on hospital committees to improve pediatric palliative care and family-centered care. Parents are childhood cancer awareness advocates. Parents support families of newly diagnosed children or families who have also experienced a child's death. Parents participate in research in various capacities, including facilitating tumor tissue donation to advance research, partnering with physicians to publish scientific findings, lobbying for legislation that would fast-track the U.S Food and Drug Administration's approval of new pediatric cancer medications, and participating in this nursing study to advance understanding of the parental bereavement experience. In addition to involvement in the childhood cancer community, parents have also created non-for-profit organizations and engaged in volunteer work. While there is diversity in the nature and scope of these activities, each has special meaning for parents.

Parents have found meaning in these activities which honor their child's memory, shape their life purpose, soothe their suffering, and give meaning to their child's death. Some parents find meaning in activities that are done in honor of their child's memory. When Joan volunteers at a shelter to feed the hungry, she explains:

I say to myself, 'I'm doing it in [Joshua's] memory'. I'm doing it because he couldn't do it, because he is not here to do it and if he was, he would do something nice for someone else and so I'm gonna be the person who does it in his memory. (pg 65, lines 4-7)

As Emma lives her life each day, she does so in Dorothy's honor and explains, "in [Dorothy's] honor, [she] would not want [me] to just give up [my] life. To honor your child is to go on with living. That's how I honor her" (pg 80, lines 8-10). Activities can present parents with a renewed life purpose. When Sara helps other families and participates on hospital committees, she explains:

You want to put your life into something that matters and may make a difference for other people...it's important to...put my life in something that is useful now, not to wait because I don't know how long of a life I will have. (pg. 68, lines 3-4, 9-11)

Activities can ease parents' suffering and offer hope for healing. For example, Kelly's sense of powerlessness over Sam's death is somewhat eased by helping other people. Kelly explains, "I just want to be able to do what I can do for people...I just want to know what I can do for Sam because I feel helpless" (pg 77, lines 19-21).

Doris' suffering is relieved by participating in research. Doris explains:

I feel compelled to do something... I'm just hell-bent...I have a real passion for furthering research of any kind as it pertains to kids and cancer...I find the thing that...that helps my...grieving, or...my emotions, is doing something for research, doing something that will stop [childhood cancer] so nobody else has to do it. Ultimately, I don't want anyone else to have to feel this way...nobody should bury their child. (pg 130, lines 7-10; pg 131, lines 11-16)

Finally, some parents are searching for activities that may offer some meaning to their child's death. Peter explains:

I'm hoping that there is a something for this...something is going to have to come out of this. I didn't get to donate his tumor tissue or donate an organ or...save somebody else's kid [to help] some father and all of that still bothers me today. His death meant nothing...I need a *something* [emphasis added] and what that something is, I have no clue...I want a something from all this. And yeah another foundation will have \$5000 and [I could] give money...sounds

great, it really does. I haven't thought of it yet and it's redundant because 25 parents before me have already done this. So maybe my efforts will be better spent supporting their foundations that's already up and running and collecting whatever monies in honor of...the Christian foundation or the Amy's army...rather than having 45 fractions collecting \$5000 dollars each. I don't know. One day I'll have an answer. One day it'll be better...I hope. (pg 21, lines 8-11; pg 35, lines 17-23; pg 36, lines 1-2)

As parents participate in meaningful activities, they create their child's legacy.

Joan, for example, has created Joshua's long-lasting legacy through her work to feed the hungry and through her efforts to establish a non-for-profit organization with a mission of sending thoughtful cards of well wishes to sick children. Joan explains:

I say to myself 'I'm doing it in his memory'. I'm doing it because he couldn't do it, because he is not here to do it and if he was, he would do something nice for someone else and so I'm gonna be the person who does it in his memory. (pg 65, lines 4-7)

Creation of the child's legacy through meaningful activities done in honor of the child's memory brings meaning to the child's death and gives a parent a renewed sense of purpose. All parents need something of meaning to come from their child's death. What brings meaning is very different for each individual parent. While some parents have found varying degrees of meaning through activities, others are desperately searching. Peter states, "His death meant nothing...I need a *something* [emphasis added] and what that something is, I have no clue" (pg 21, lines 8-11). Peter's search for meaning is not unlike that of other bereaved parents. It is widely recognized that parents do indeed experience a crisis of meaning as they struggle to make meaning of the profound loss of their child (Braun & Berg, 1994; McIntosh, Silver, & Wortman, 1993; Wheeler, 1993-1994; Wheeler, 2001).

When parents do find meaning, suffering is eased. Studies indicate that when bereaved parents are able to find meaning, grief lessens in intensity (Keesee, Currier, & Neimeyer, 2008; Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Lichtenthal, Neimeyer, Currier, Roberts, & Jordan, 2013), mental distress decreases (Murphy, Johnson, & Lohan, 2003), and overall physical health improves (Murphy et al, 2003). Further, meaning helps people find hope as they cope with loss (Harvey & Miller 1998). Frankl (1959) states, “in some ways, suffering ceases to be suffering at the moment it finds a meaning” (pg. 113). Cassell (1982) adds, “assigning meaning to the injurious condition often reduces or even resolves the suffering associated with it” (p. 644). Findings from this current study illuminate the search for meaning that occurs throughout bereaved parents’ lifelong journey towards healing.

Faith

Faith is an aspect of the parental bereavement experience. Parents in this study represent different faiths, including Jewish, Baptist, Episcopal, Evangelical Lutheran, and Roman Catholic. To varying degrees, faith sustains parents after the death of a child. For some, faith grows stronger and becomes a very important source of support. For others, faith is challenged and is not a significant source of support. This continuum of faith contributes to the diverse nature of the parental bereavement experience.

Faith is a source of support. For many parents, faith is a significant support.

Faith sustains parents along their journey towards healing by counteracting grief, giving strength, and giving hope.

Faith counteracts grief feelings of loneliness and isolation. Emma explains:

My faith is really what has gotten me through...I think the good Lord sent me to the right places and gave me the right friends...I know He's there for me...I can talk to the good Lord and he understands me...if I didn't have my faith and my church, I would feel like I really was alone. (pg 36, lines 16-18; pg 80, lines 21-22; pg 81, lines 6-7)

Faith gives parents strength to endure suffering. For example, in spite of feeling abandoned and angry with God, Joan credits God's intervention and a spiritual awakening with saving her from self-harm (pg 50, lines 22-23; pg 51, lines 1-11). In this way, faith has been a source of strength for Joan. Joan explains:

I made a decision that I did want to...die. I was *glad* [emphasis added] that I didn't jump in the hole [when Joshua was buried]...It wouldn't have done anybody any good, me or anybody else. I think that would have just made it more difficult... I started to get some kind of pleasure back out of my life...by little things... I don't think it was anything that I did. I think it was something God-like that had happened, like a spiritual awakening... I don't remember any moment that it happened. I think it happened over a series of time. (pg 51, lines 2-11)

Faith gives Sara somewhere to turn in the midst of suffering (pg 40, line 20), be it "resting faith" or "clinging faith" (pg 41, line 8). Sara explains the difference:

There are times in our lives that I just think we are walking along and we feel like even if we do have some kind of a faith, we feel like we are pretty much ok and don't need it... and sometimes it will take difficult times in our lives to makes us really dig deep into the faith or to turn to that faith. Sometimes you are just clinging because that's all you can do, things are just so difficult and other times, you're able just to rest knowing...like, even though we have been through a lot, I really truly believe that God wants what's best for us. He loves

us. He cares about each of the things that is going on in our lives and so...I can rest in that. (pg 40, lines 22-23; pg 41, lines 1-2, 2-4, 7-9, 11-14, 16)

Sara has been able to endure as a result of her faith becoming stronger after Adam's death. Sara explains:

I had faith before all of this happened, [but] I do believe that when you go through something like this...it makes everything so much more real...Heaven is much more real for me...I always taught my children that Heaven is a real place, just like [Bridgeport, Connecticut] or just name any city...I always taught them that, but this made that very real for me. (pg 42, lines 9-11; pg 43, lines 10-12)

Prior to Adam's death, Sara was fearful of the death process. Now, however, she is no longer fears death because of a deeper faith that came from holding Adam in her arms as he died. Sara explains:

Before all of this happened, if someone were to ask me, if I'm being honest, I would have said I was afraid to die not because I'm afraid of eternity but because I was afraid of going through the death process, just not being sure of that. Now...I can say, because I held my son in my arms while he died...I am not afraid of dying because of what I have seen (pg 42, lines 20-21; pg 43, lines 1-4, 7-8)

Sara "trusts and rests in the Lord" (pg 43, line 4), knowing that the Lord wants what is best for her and her family because of the "little gifts of loving kindness" that the Lord has given her along the way (pg 45, lines 1-5, 16-17; pg 50, line 9-10). One of these gifts came when Adam was still alive. In spite of how sick Adam was, he wanted to attend the Thanksgiving prayer service at church to pray and give testimony thanking God for all He has done. At the time, Adam was having tremendous difficulty with speech to the point that Sara had to interpret for him. As it so happened, a deaf woman was in attendance that particular night rather than attending her usual morning

service. Because Sara was the deaf woman's interpreter, Sara was standing upfront facing everyone, including Adam. Because she was facing Adam, rather than standing next to him, she could see Adam mouthing the words to all the hymns (pg 48, lines 5-7, 9-11, 13-16, 18-19, 21-23; pg 49, lines 1-2, 4-6, 8-13, 15-17, 19-22). Sara explains:

That was just a gift from God. It was. Just letting me see that...his joy to be there...to sing along to all the hymns, even though...he couldn't make his voice work like we think it should...but he was mouthing all the words to the different hymns... it was just such a blessing...I feel the Lord just gave us little bits, little gifts of loving kindness along the way...and that was certainly one of them...so, if that lady had not had come, I would have just been facing the front...and she has never come at night since... that was a Wednesday and it was exactly a week later...that he went to sleep...he never woke up after that. (pg 49, lines 22-23; pg 50, lines 2-3, 5, 7, 9-10, 12, 14-15, 17; pg 51, lines 7-8)

This memory remains very powerful more than two years after Adam's death and provides an example of why her faith strengthened as a result of her experience.

Faith gives parents hope. Hope means different things to different parents.

Faith gives parents hope that their parenting relationship will continue. Joan explains, "I do believe that when you die, you just no longer exist....I believe there is something and [so], I strive to have a relationship with him now that he's not here" (pg 65, lines 11-12). Faith gives parents hope that they will see their child again one day.

According to her faith beliefs, Sara explains that if you accept Christ as Savior you will go to Heaven and be with Him for eternity (pg 39, lines 19-20, 22-23; pg 40, lines 2-3). It is this faith belief that gives Sara the hopeful knowledge that she will see Adam again (pg 40, lines 3-4, 6-7, 15-16). Sara explains:

I have hope. I will see him again...even though right now it is difficult... for him not to be with us...That is hard for us... but, because of my faith, I

believe that I will see him again... that is one reason [my faith] has been a help to me. (pg 40, lines 7, 12-13, 15-16, 18)

Kelly's faith belief of an afterlife gives her hope that she will see Sam again one day.

Kelly explains:

I know that he's got to be in a different place that in this hell. He's got to be... There's got to be an afterlife. There has to be... I know deep in my heart... that we will meet up again. I know that. I know that. I'm holding on to that dream that... one day he will hold me and that I'm hoping [so] much... there is this hope that we'll be together again. Definitely, it keeps you going. No question about it. No question about it. (pg 25, lines 9-10; pg 30, lines 13-14; pg 58, lines 5-7; pg 141, lines 2-4; pg 142, lines 11-12)

Kelly is sustained by the hope that her faith brings. Emma is also sustained by hopeful faith that she will see Dorothy again one day in Heaven. Emma once wrote a story about this and explains:

The story takes off where I'm walking along and I've got an angel beside me... when I get into Heaven,... my Dad and my Mother and my Grandpa... they're all right there... we're all laughing and happy... all of a sudden I felt these little arms around my neck... and I turn around... I looked into her blue eyes and I said... I finally know this is Heaven because I have her back... I pray that that's the way it's going to be someday. I'm not in too much of a hurry for that. (pg 37, lines 1-9)

Faith can also give parents hope for healing. Sara's faith gives her hope that she will have peace. Sara explains:

The Bible says that you can have peace. This is what scripture says. We know that to be absent from the body is to be present with the Lord and so you can have peace... If we were teaching our son that and expected [him] to believe that so he would not be afraid,... then... how can we not believe that ourselves? (pg 51, line 14-19)

Kelly also has faith that healing will eventually come and says:

Do I think things will get better? I know they will...I know I'm going to feel better once I see Sam, feel Sam, dream of Sam...I think once I get over that, then I think...I can start my life again. (pg 107, lines 4-7)

Finally, faith can give parents hope that something meaningful will come from the horrific tragedy of their child's death. Peter explains:

I'd like to think that God has a plan for me. I have no clue what it is. I'm hoping that there is a something for this. Not that I'm going to get paid, but something is going to have to come out of this. I didn't get to donate his tumor tissue or donate an organ or... save somebody else's kid [for] some father and all of that still bothers me today. His death meant nothing...I need a *something* [emphasis added] and what that something is I have no clue. (pg 21, lines 8-14)

While some parents are able to lean on their faith for support, other parents cannot.

Faith is not a strong source of support. For some parents, their faith has been challenged and doesn't serve as a strong source of support. Parents feel abandoned and sometimes angry with God. Joan shares her experience of feeling abandoned and angry with God for allowing Joshua to get cancer and die in spite of her being a good person and always trying to do the right thing (pg 21, line 15-20; pg 50, lines 10-12). Joan explains:

My husband and I were walking around the lake one day when our son was ill... and there was these two little boys by the lake and they didn't have shirts on...it was a spring day, but it wasn't extremely warm out... and I said to my husband, 'There is no adult around and they are by a body of water' ...they must have just...been around 7, 8, 9, 10 [years old]...I would *never* [emphasis added] leave my child by a body of water like that without my husband or I sitting right there staring at them. I wouldn't even leave them by a bucket. I mean, you could drown in a bucket. We watched our children breathe *in and out, in and out* [emphasis added]. I watch everything that my children do. How can my son have cancer and these two little boys [are] sitting by this lake unsupervised?...we came up with the conclusion that God must be too busy watching them to watch my son and He's leaving the ability for somebody to watch our son to us...It's just like, why? That is the big question. Why me?

Why him? Why my child? What did I do to deserve this? What did he do to deserve this? He was only *nine* [emphasis added]! What could he have done to deserve getting cancer when there are people in the...world who kill and rob and steal?...When I first had children I always thought if you did the right thing, the right things is gonna happen. So I always had my children do the right thing. I always tried to do the right thing and then my child gets cancer...I was mad at God for a very long time, still mad at God. I think I have a different God in my life today than I used to have in my life...how could this happen to my child? What did I do to deserve this? What did he do? Just someone *tell me* [emphasis added]...I never got an answer. I got an answer to why did my mother die so young, so she didn't have to see myself and my son suffer, but why did my son have to die so young?...after my son died, I struggled with my faith. I struggled with God. I was talking to God. I was totally mad with God...I think even when I was mad with God, God wasn't mad with me and it was ok that I was mad about it...God turns his back on me and look what happens to my son. I don't know what the answer is. I don't know if God works in that way or [not]. (pg 20, lines 17-23; pg 21, lines 1-23; pg 50, lines 8-14)

Although Doris isn't angry with God like Joan is, she too feels abandoned; hence, her faith is no longer a source of support. Doris explains:

I've always considered myself a fairly faith-filled spiritual person... I'm not participating actively in a strong prayerful life like I once had. I don't feel able to seek out my faith as a place of support. I know that I continue to believe that I will see Cindy someday. I continue to believe that Cindy is in a better place. I continue to believe in God. I just feel it's another area where I feel abandoned...I feel like God abandoned me. (pg 134, lines 7-13)

Besides feeling abandoned by God, Doris also feels abandoned by her pastor (pg 134, line 18; pg 135, line 9) and church friends (pg 134, line 29; pg 135, line 9). Although she surmises the reason that her pastor and church friends no longer reach out to offer her support is because they must be attending to others in need, she nevertheless is angry about it (pg 135, lines 9-12). To Doris, it feels like they no longer care (pg 135, line 8). This contributes to feelings of abandonment in regard to her faith. In addition,

it is very difficult for Doris to be inside of the church. It triggers a heightened sense of Cindy's absence and, therefore, a greater intensity of grief because church was a central part of Doris' life with Cindy (pg 137, lines 6-7) and also a place where other families with children are in attendance (pg 134, lines 15-16). Doris says, "it's one more area that isn't fun and isn't comfortable" (pg 137, lines 14-15). Doris has considered going to a different church, but has not yet done so (pg 135, lines 22-23). Doris explains, "it just isn't enough for me to go and sit in the sanctuary and listen to music and pray and know that someday I'm gonna feel better, because frankly I'd like to feel better right now" (pg 137, lines 15-17). Experiencing intensified grief when inside the physical space of the church, as well as feeling abandoned by God, pastor, and church friends have all served to shaken Doris' faith and weaken the amount of support faith might otherwise offer.

Just as Doris felt abandoned by her pastor when he withdrew support, Emma found herself adrift in parental bereavement without the support of a priest for a very long time. Emma searched for priests who might offer some support to no avail. Emma explains, "I went to different priests to talk and see if they could give me any kind of help. I didn't get any" (pg 34, lines 15-16). It was only after some time that Emma eventually met a priest who offered her a small amount of comfort. Emma explains:

He was the first one who made any kind of sense. He said that there was a possibility that maybe the good Lord saved her from something far worse...I've often thought about that and...he could have probably been right! So, it gave me a little bit of comfort to know that. (pg 34, lines 18-23)

For Emma, this priest assisted her to make some sense over her daughter's death and, as a result, eased Emma's suffering

Why?

Along the journey toward healing, parents wrestle with the question as to why their child died. This question is difficult, if not impossible for parents to answer. As Peter and Joan try to make sense of why Robert and Joshua died, they wonder if they themselves are to blame. Peter says:

I feel that I must have done something really bad to deserve this. Is it just Catholic guilt? It could be...I must have done something really bad to deserve this. That's how bad it is...being in prison the rest of my life wouldn't be this bad. It wouldn't be a picnic, but it wouldn't be this bad. (pg 25, lines 6-10)

Among many things, Joan has wondered if Joshua died from cancer because she of her fears that she wasn't a good mother. Joan explains:

Maybe, my worst fear was true...I'm such a defective person that...it's something that I did that caused him to have this cancer...I don't know what it is, but I'm sure that I'm to blame for it...I'm sure that it's something that I did...I thought that there has to be something that I did...I still have days like that...[but] for the most part it has passed. (pg 13, lines 5-9; pg 14, lines 2-3)

Like many parents, Doris believes there was neither a specific reason why Cindy died nor that it was God's plan (pg 118, lines 10-11, 13-14). Doris explains:

Some good may come of it, but I don't think it happened for a reason... Maybe me talking to you will make me feel better. Maybe I'll say something that will help you to help your [nursing] students... maybe there can be good that comes of it, but I just don't think it happened for a reason. I don't think...God looked down and said '*Ah ha! Doris Smith, she can do this [emphasis added]!*'...I just don't buy that" (pg 70, lines 7-8, 10-14)

Sara says, “we don’t know why this happened. I don’t think that everything that happens is because you have done something wrong” (pg 33, lines 17-19). It is very distressing to Sara when people suggest the reason that Adam got cancer and died is because of a lack of faith. Sara tells the following story:

I did actually have someone when Adam was alive say that if we had enough faith he would be healed. *And I’m a Pastors wife* [emphasis added]! *I have faith* [emphasis added]!...what she went on to say is insinuating that maybe there was something...we did or what we didn’t do, or how much we prayed. When you say things like that, or even the little comments like that, like...let’s say that Johnny is going to have a scan today and they find that the tumor is stable and the response is ‘God is good’ or ‘God is on our side’. Whenever I see that now...I think differently... does that mean God is not good or that He is not on my side because my son has died? I don’t feel that God is not good because my son died. (pg 34, lines 17-23; pg 35, lines 1-8; pg 36, lines 11-12)

Emma also wrestles with this question and is resigned to the fact that she will never know the answer. Emma explains:

I still feel like ‘Why? Why can’t she be with me? Why?...I remember my mother-in-law at the time, her and I...we were talking and she said, ‘well, we’ll never know why until we get to Heaven and then we won’t care’...I never forgot that because...that’s how I feel now...it’s just like the older I get, the more...I accept it. I have to accept it, but I still in some ways [don’t], but then I think...well, we’ll never know. (pg 23, lines 18-22; pg 34, lines 13-15)

Emma, Doris, and Sara’s experience is not unlike other bereaved parents. In a mixed methods study, Lichtenthal and colleagues (2010) examined sense making and benefit finding as 156 parents, the majority of whom were Caucasian mothers who experienced the death of a child less than 47 years of age due to a wide range of causes, made meaning of their loss. Most parents indicated that no sense could be made of their loss.

The unanswerable question of why often brings with it a sense of injustice.

Kelly explains:

A parent, a grandparent ...they've had probably a good quality of life by the time they've passed on, but a child has had no time...but suffered. It just makes no sense and to this day, I always say...I always say it makes no sense...[Sam] was a very special young man, a very special young man. It's just not fair. It's just not fair. He had so much potential. He was extremely fit. He was healthy. (pg 41, lines 2-5; pg 62, lines 11-13)

Emma also talks about the unfairness of a child's death, saying, "I know it's not right to say 'it's not fair', but to me it's not fair for any mother to have to go through that"

(pg 17, lines 18-19). Doris specifically pinpoints the underfunding of childhood cancer research as a major injustice. Doris explains:

The month of October, [National Breast Cancer Awareness Month], in general just wants to make me scream with anger...childhood cancer research being so totally underfunded...and while I am ever eternally grateful for breast cancer research, just the fact that they spend two-three times per month on breast cancer research than on childhood cancer research just makes me [feel] like Cindy didn't even have a chance to have hope *for crying out loud* [emphasis added]. (pg 81, lines 4-11)

Hope

Hope is an aspect of the parental bereavement experience. Hope sustains parents along their journey towards healing. Parents hope for many things. Parents hope that with each passing year of parental bereavement, grief will lessen, suffering will ease, and life will change for the better. Kelly states, "my God, I don't want to say in 5 years, in 10 years' time I'm going to be in this so-called slump that I am in...Do I think things will get better? I know they will" (pg 101, lines 3-5; pg 107, line

4). Doris states, “I hope at some point I have a place where...I’m able to live with a little less sadness” (pg 71, lines 4-7). Peter states, “one day it’ll be better...I hope” (pg 36, line 2). Joan states:

Still, I don’t celebrate New Year’s. Every year is just another year for me without him...I try to say to myself, ‘Well, maybe next year will be better’, ‘Maybe I’ll feel different next year’...I want to leave it open to the possibility...that maybe one day I will be feeling good about New Years Eve, or the possibility of...things changing and getting better. (pg 31, lines 8-14)

Parents have hope that they will see their children again one day. Faith is what keeps this hope alive and strong. Sara explains that, according to her faith beliefs, if you accept Christ as Savior you will go to Heaven and be with Him for eternity not because of anything you did or didn’t do, but because of what Christ did for you and because of this truth Sara knows she will see Adam again (pg 39, lines 19-20, 22-23; pg 40, lines 2-3; pg 40, lines 3-4, 6-7, 15-16). Sara states, “I...know without a doubt that I will see him again...I have hope. I will see him again” (pg 40, lines 3-4, 7).

Kelly shares this same hope. Kelly states:

There’s got to be an afterlife. There has to be...I know deep in my heart... that we will meet up again. I know that. I know that...I’m holding on to that dream that...one day he will hold me and that I’m hoping too much...there is this hope that we’ll be together again. Definitely, it keeps you going. No question about it. No question about it. (pg 30, lines 13-14, pg 58, lines 5-7, pg 141, lines 2-4; pg 142, lines 11-12)

Parents also have hope for other families in the future. There is the hope that other children won’t die from cancer, the hope that other parents won’t have to experience parental bereavement, and the hope that if they do that they will receive more supportive care than they themselves have received. For example, Emma states

“I would hope that any parent today that goes through that horrible thing that there would be people there that would try to understand and try to be helpful to them. I really do pray” (pg 27, lines 11-13). It is this trilogy of hope for a better future for other families that helps to fuel parents’ participation in many meaningful activities.

Hope is the foundation of Doris’s meaningful work in the childhood cancer community and Emma’s meaningful participation in this nursing study. Doris explains her reason for staying connected to the childhood cancer community is so she can help and states:

Doctors and people who can do something so that other kids don’t have to do this. That does bring me hope...it really does...I don’t want anyone else to have to feel this way...nobody should bury their child. (pg 130, lines 16-20; pg 131, lines 14-16)

Emma explains her reason for wanting to participate in this nursing study is so she can help other bereaved parents, stating:

Out of all my circle of friends, the bereaved mothers, I was the only one who actually filled the...the things you wanted...you wanted someone who died of cancer, someone under 18, someone who had been gone more than a year.... when I read the paper and saw what you needed, I thought ...I could help mothers that have to go through it. I hope that I can. (pg 12-15, 19-21)

Chapter X

SUMMARY, STRENGTHS AND LIMITATIONS, AND IMPLICATIONS

Summary

Five mothers and one father, having experienced the death of a young child due to cancer at least one year prior, volunteered to participate in this Heideggerian, hermeneutic phenomenological study describing the lived experience of parental bereavement. Van Manen's (1997) method guided concurrent data collection and analysis, which unveiled the following essential thematic aspects of the parental bereavement experience: a) new state of being; b) profound suffering; c) continued parenting relationship; d) self-renaissance; and e) journey towards healing. From these essences, a holistic structure of parental bereavement emerged.

Parental bereavement is a new state of being in which, after the death of a child, the parent endures profound suffering incomparable to the likes of any other, maintains a lifelong parenting relationship in the presence of the child's absence through acts of remembrance and honor, experiences a renaissance of self, and journeys towards healing sustained by support and hope. This is the nature of what it means to experience parental bereavement. *Precious Child* (Appendix D), a song by Grammy-nominated songwriter Karen Taylor-Good, illuminates the parental bereavement phenomenon. The song's lyrics poetically reflect the lived experience of

parental bereavement, for as Kelly states, “that song, that prayer, says it all” (pg 91, line 13).

This rigorous, trustworthy study deepens understanding of the meaning of the lived experience of parental bereavement. This study makes a significant contribution to nursing science. Never before has the meaning of parental bereavement, as lived by parents who experienced the death of a young child due to cancer in the United States, been captured so holistically. This study has important implications for nursing research, education, and practice.

Strengths and Limitations

The strong methodological design of this Heideggerian, hermeneutic phenomenological research study spawns credible, trustworthy findings. This study contributes to the body of phenomenological research informed by van Manen’s (1997) method and further validates this methodological approach to human science research. Concurrent data collection and analysis unveils a structure of parental bereavement that has never before been so holistically described. The study’s aim, to describe the lived experience of bereaved mothers and fathers who have experienced the death of a child due to cancer, was met.

Six parents provided rich and thick descriptions of their experience from which a structure of parental bereavement emerged. The structure represents one interpretation of the parental bereavement experience as it is lived by these parents of

different faiths and different geographical regions of the United States. One must take caution not to generalize findings to other populations, such as bereaved parents who have experienced a young child's sudden or violent death or bereaved parents who have experienced the death of an adult child. Future studies exploring the meaning of the lived experience of parental bereavement among these populations are warranted.

This study would have benefitted from a greater representation of fathers; however, the one father who did participate provided a rich description of his lived experience which does advance knowledge of this historically underrepresented population. It was my hope that more fathers would have participated. In spite of focused efforts to garner additional fathers, none meeting inclusion criteria came forward to volunteer. Three fathers who expressed interest did not meet inclusion criteria. One father experienced the death of a young child due to cardiac disease, one experienced the sudden death of a 19 year old child after a viral illness, and one experienced the deaths of two young children within a two year time span due to different non-oncologic causes. It is unclear why more fathers within the study's inclusion criteria did not volunteer to participate. This is an area that merits further investigation. Future studies perhaps might be less restrictive with inclusion criteria so as to maximize the amount of fathers who participate. The design of future studies also merits consideration. Perhaps future studies may be designed in such a way as to gather material about fathers' lived experience of bereavement not solely from traditional interviews per se, but from alternative sources such as narratives, blogs, or

social media. Clearly, opportunity to better understand fathers' lived experiences of parental bereavement exists and is very much needed.

The depth and breadth of each parent's experience is remarkable. My ability as a nurse researcher to establish trust and maintain true presence with each of the participants, regardless of whether an in-person or telephone interview was conducted, is evident in the vast amount of material gathered during interviews. While I would have preferred to conduct every interview in-person, it was not feasible given the considerable geographical distance which prevented doing otherwise. Nonetheless, the telephone format of three parents' interviews did not deter those parents from sharing their incredibly powerful experiences in great detail. Material gathered from telephone interviews were just as rich and thick as material gathered from in-person interviews. I felt no difference between the two. Both were equally powerful. While in-person interviews afforded me the opportunity to observe parents' non-verbal communication and observe parents in their familiar surroundings, telephone interviews also proved to be beneficial in their own way. Telephone interviews provided the greatest flexibility for parents to talk at a time and place that they most desired. For example, Sara's first interview was conducted while she traveling in a car driven by her husband to attend a memorial service for a family member who died unexpectedly. Upon learning this, I initially was concerned that conducting Sara's interview at that time would be suboptimal. My concern stemmed from an erroneous initial presumption that Sara would be under heightened distress which, when coupled

with the fact that she was in the presence of her husband, might influence her response and limit her from speaking freely. Sara assured me that this was not the case and that the time, in fact, was best for her. When I suggested that we might consider rescheduling her interview to more convenient alternate time, Sara stated, "I'm fine... we are actually going to be traveling for hours so I am fine...I'm okay. I really am. This is a probably pretty good time because I can't really do a whole lot of anything just sitting in a car" (pg 1, lines 13-14, 17; pg 2, lines 3-4). Had the study design mandated in-person interviews only, Sara would have been forced to carve out separate time that she may not have otherwise had. Sara also would have been denied the opportunity to participate and share her story since it would have been impossible for me to travel across many states to meet with her in person. Telephone interviews also afforded participants the greatest flexibility to take breaks when they wished. All participants were encouraged to take breaks whenever they wanted; however, only participants who completed telephone interviews chose to do so. Sara chose to take a short, five minute break when making a rest stop on the drive with her husband. Doris also chose to take a short, one hour break when her son returned home from school and she wanted to move to her bedroom in order to continue her interview in a quiet, private space. Perhaps parents felt more empowered to take breaks during telephone interviews than during in-person interviews. It is possible that parents who interviewed via telephone may have perceived a greater sense of control over starting and stopping their interview whenever they wished. My physical presence while

conducting in-person interviews with parents in the restaurant, in the car, and in the home may have unintentionally deterred parents from choosing to take a break when perhaps they may have wanted to but were hesitant to say so. Throughout in-person interviews, I continually assessed for non-verbal cues that might suggest breaks would be helpful; however, each parent was fully invested and eager to tell their story throughout the entire interview. It was as if they couldn't tell their story fast enough and any break would have been a hindrance. Encouraging and assessing participants' need to take breaks during interviews, whether in-person or via telephone, is especially important when conducting research with vulnerable populations such as bereaved parents. Although all parents were encouraged to take breaks whenever they wanted, it is interesting that only parents who completed telephone interviews actually did.

Findings from interview material provide evidence that parents positively view their study participation. Parents found meaning in their participation, were thankful for the opportunity to share their lived experience, were comforted by being able to talk about their lived experience, and expressed hope that their participation will help other bereaved parents in the future. These beneficial outcomes of study participation are evident in parents' statements. Joan states, "I hope I can just help somebody with even just one tiny thing that I say...that I could help a bereaved parent" (pg 64, lines 19-23). Sara states:

I appreciate the fact that you are doing this project. Things like this really mean a lot to me. I just think it's good to see someone looking into these types

of things and trying to make things better for other families in the future. (pg 37, lines 11-14)

Doris states, “I appreciate you letting me talk... it feels good to have somebody listen and ... if there is anything you can glean from it that you can help...other patients’ parents” (pg 50, lines 20, 22-23; pg 51, line 1). Doris adds, “sometimes I cry and it’s hard. It still feels good. It still feels like the right thing...it’s kinda hard, but ...it’s not a bad hard. It’s a good hard...thanks for giving me a voice. That is helpful too” (pg 138, lines 20-23; pg 139, line 5). Emma echoes Doris’ sentiment, saying “you’ve helped me too... you listen to me and let me express myself. It’s hard...it’s really sometimes hard to do but, you have helped me a lot” (pg 90, lines 5-7). Emma adds:

Most of my friends didn’t lose their children...to cancer. They lost them like to accidents and things and they were older, so I felt like I could kind of contribute to this... ‘cause you had asked for...a younger child and someone who had died of cancer, so...that’s why I thought that maybe it would be useful...I would be glad if I could help... when I read the paper and saw what you needed, I thought it would, you know I could help mothers that have to go through it. I hope that I can. (pg 8, lines 7-11, 13; pg 58, lines 21-22; pg 90, lines 19-21)

There is healing in helping others. It is quite possible that, as a result of their participation and partnership with me on this research study, they have traveled a little farther along in their journey towards healing.

This research endeavor has been absolutely amazing. I have searched and searched for ways to articulate my journey in partnering with six bereaved parents to unveil the meaning of their lived experience in a way never before understood. I seem to fall short every time I try to describe what it has been like, but amazing is the one

word that has repeatedly come to mind. I have learned so much about phenomenology as both a philosophy and a method. I have a greater appreciation for the rigor of qualitative research. Always one to give due diligence to any endeavor, I felt compelled to do my very best as a beginning researcher so that I would do right by the parents, honoring them and their children. While I will never be able to completely understand what it is like to be a parent who experienced the death of a child, as that is not my own lived experience, I feel that through my partnership with parents a little more light has been shed on the meaning of the lived experience of parental bereavement. I bore witness to parents' suffering and feel an obligation to articulate their lived experience as fully and deeply as possible.

Reflecting back to an earlier point in this research, I am struck by a comment made by a prominent nurse researcher. I discussed with her my research proposal to describe the lived experience of parental bereavement. Her response was, "Why would you study the lived experience of parental bereavement? Once the child dies and the family leaves, nurses have nothing more to do with the family so there is no point in your study and I strongly advise you to look at a different aspect, such as grief support group outcomes" (field note log, pg 30, line 46; pg 31, lines 1-4). At the time I couldn't clearly articulate the significance of such a study, although I knew the gap in the literature was real and I sensed a need to gain a better understanding of what bereavement, not grief, is from parents themselves. With the support of my dissertation chair and committee members, I stayed the course. After prolonged

engagement in the field, completion of extensive interviews with six parents, and deep immersion in data analysis, I have since learned here-in lies the problem: the fact that nurses have nothing more to do with the family after a child's immediate death and that nurses are in some way done with nursing care are misconceptions. This is not how it ought to be. There is great opportunity and much obligation for nursing to do considerably better. I have been continually reassured by numerous informants, colleagues both in nursing and medicine, parents who were interested but whose experience did not meet inclusion criteria, and most especially the parents who did participate that nursing science needs this study. Implications for research, education and practice abound.

Implications for Research, Education, and Practice

This nursing research study, grounded in phenomenology, makes a significant contribution to nursing science and advances nursing knowledge of the meaning of the lived experience of parental bereavement. This study has important implications for nursing research, education, and practice.

Research. Bereavement-related literature has expanded in recent years. Studies showcase theoretical evolution and offer developing insight of specific aspects of the bereavement experience, such as grief, continuing bonds, and meaning-making particularly in mothers who experienced a child's death from various causes and at various ages. In spite of ongoing scholarship in the field, a holistic description of the meaning of the lived experience of parental bereavement has eluded nursing science

until now. This study fills that gap. Findings from this study illuminate the immense meaning of the lived experience of parental bereavement. Findings must be disseminated through scholarly publications in peer-reviewed journals and professional presentations at scientific meetings.

With a deeper understanding of the meaning of the lived experience of parental bereavement among a sample of five mothers and one father who experienced the death of child, less than 18 years of age, due to cancer at least one year prior, a foundation to build a program of nursing research is now in place. Opportunities for future scholarly inquiry are plentiful. Nursing research is needed to expand understanding of fathers' parental bereavement experiences. Nursing research describing the lived experience of mothers and fathers who experience the sudden and/or anticipated death of a young child due to non-oncologic causes is merited, as is research describing the lived experience of mothers and fathers who experience the death of an adult child. As one support group informant shares:

We have several parents in the group whose children died from Cancer but their children were older than 18. I tell you this because I want to impress upon you that no matter what the age of the child, the grief suffered by these parents is deep and profound. It seems that society, in general, has more sympathy for parents who suffer the death of a young child, still at home, taken at a young age but sadly our group is composed mostly of parents of adult children (over 21) who have died. They come to our meetings and remain active in the group mostly because family and friends expect them to "be over it" much sooner than they are able recover -- we become for each other the support, comfort, and safe haven that they cannot find out there in the "real world". I think it is important for hospitals to understand that any adult patient dying from cancer, unless they are of an advanced age, will have parents who may be pushed to the background, while the spouse and perhaps their children receive the major share of concern, sympathy and caring. Hopefully in raising your awareness,

this concept will trickle down to your colleagues and more attention will be paid to the parents of adult children who are dying from any cause. The parent/child bond remains no matter how old the child becomes. (Informant personal communication, e-mail, May 26, 2011)

Perhaps commonalities and uniquenesses exist among all lived experiences of parental bereavement, but unless nurse scholars go directly to the individuals who are living the parental bereavement experience that remains uncertain. Nursing research needs to fill this gap; otherwise, nursing will continue to fall short in meeting its obligation to minimize suffering by assisting parents throughout lifelong bereavement. For as Ferrell and Coyle (2008) state, “the relief of suffering is at the core of nurses’ work (p. 102).

Findings have important implications for future research with bereaved parents. While bereaved parents are indeed a vulnerable research population, parents value their participation. This study adds to the body of literature regarding beneficial outcomes of bereaved parents’ research involvement (Brabin & Berah, 1995; Hynson *et al.*, 2006; Meert *et al.*, 2008; Scott *et al.*, 2002). Based on what I have learned in partnering with study participants, I offer several recommendations for conducting nursing research with bereaved parents. First, ensure parents have available access to social support through formal in-person or on-line support groups and/or professional counseling so that they can call upon additional support if needed. Second, meet parents on their terms. Some may prefer to meet in a public space and share a meal while engaged in interview dialogue. Some may wish to meet in the safe comfort of their home. Some may feel most comfortable meeting in a familiar environment

surrounded by nature. Some appreciate the flexibility that a telephone interview meeting offers. Third, allow parents as much time as they need to complete the different aspects required of their participation. For example, allow ample time for parents to read the informed consent and come to a decision as to whether or not they wish to participate. Allow time for parents to relay their story and encourage them to take breaks if they wish for as long as they wish. Allow parents all the time they need to read and comment on the interpretive summary of findings. Fourth, remain flexible. Researcher flexibility is key. While a mutually convenient interview time may be agreed upon, parents may change plans at the very last minute. The researcher must remain flexible and assure parents that the interview can be rescheduled to a more convenient time. Fifth, parents benefit from frequent reminders regarding upcoming scheduled interviews. Best practice would be to communicate one week, two days, and once again within 24 hours of the scheduled interview. Frequent reminders are particularly helpful in light of parents' diminished concentration which may be part of multidimensional grief. Sixth, honor parents' preferred mode of communication. Some parents prefer telephone communication, some prefer talking in person, some prefer e-mail, some prefer text messaging, and others prefer handwritten letters. The mode of communication a researcher uses largely depends on the nature of what is being communicated. Text messaging may suffice when confirming interview meeting time, while e-mail communication is acceptable when providing progress updates. Lastly, and most importantly, it is important for nurse researchers to

maintain true presence while actively listening in a non-judgmental manner and to demonstrate compassion. A short hand-written or e-mail note acknowledging the child's birthday and deathday can demonstrate the researcher's humanity. A simple, kind gesture such as this is exactly the type of nurse caring behavior that reportedly minimizes parents' feelings of abandonment and distress. This study is testament to the fact that when nurse researchers truly partner with bereaved parents to conduct scientific inquiry on the phenomenon of parental bereavement, parents are not only afforded an opportunity to find meaning but also empowered to make valuable contributions to nursing knowledge which, in turn, will help to improve care for other bereaved parents in the future.

Education. This study has important implications for the education of nurses, other health care providers, and communities at large. A discussion of implications for each follows.

Nursing education. This study advances nursing knowledge of the lived experience of parental bereavement. Findings must be disseminated into undergraduate and graduate curricula, as well as into continuing education for licensed professional Registered Nurses and Advanced Practice Registered Nurses regardless of practice setting. During the past decade, strides have been made in pediatric palliative and end-of-life nursing education as a result of the successful implementation of The City of Hope and American Association of Colleges of Nursing's End-of-Life Nursing Education Consortium-Pediatric Palliative Care

(ELNEC-PPC) national curriculum. One of 10 modules within the ELNEC-PPC curriculum is dedicated to loss, grief, and bereavement. This module focuses primarily on grief and interventions to facilitate grieving, with only a brief explanation of bereavement as being “the time it takes to mourn, grieve, and adjust to a world without the physical, psychological, and social presence of the deceased and is highly individualized” (ELNEC-PPC, 2011, Module 9: Loss, Grief & Bereavement Faculty Outline, pg M9-6). The conceptualization of bereavement as a period of time does not reflect the true nature of parental bereavement.

In light of this study’s findings, a curricular revision is warranted. Conceptual clarification of grief and bereavement, as well as expansion of content beyond grief to include the nature of parental bereavement is necessary. Moreover, all ELNEC courses ought to be updated to reflect the study’s findings because ELNEC-PPC’s focus is to meet the educational needs of pediatric nurses and does not reach nurses who practice in other specialties. Therefore, a revision of the bereavement module within the entire ELNEC curricula would be warranted so that it reflects current scientific evidence.

Student nurses at the baccalaureate and graduate levels, Registered Nurses, and Advanced Practice Registered Nurses need to be better informed about what it is like for a parent to experience the death of a child. In *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care* (1998), the American Association of Colleges in Nursing (1998) identifies that the following

competency is necessary for high quality nursing care: “Assist the patient, family, colleagues, and one's self to cope with suffering, grief, loss, and bereavement in end-of-life care” (retrieved from <http://apps.aanc.nche.edu/Education/deathfin.htm>). Student nurses and licensed professional nurses across all practice settings need to be better educated if they are to master this competency. Pediatric nurses who care for dying children and their families have a need to better understand the lived experience of parental bereavement, as do adult nurses who care for patients who happen to be bereaved parents. If nurses are to provide high quality care and assist parents in bereavement, they need to better understand the meaning of the lived experience of bereavement. Nurses must understand that grief and bereavement are not one in the same, but rather that grief is only one of many essential aspects of parental bereavement. Nurses need to understand how their behaviors and how care processes in general will decrease or increase parents’ suffering years after a child’s death. Nurses need to understand not just the short term benefits of patient and family-centered care but also the long term outcomes. Education must emphasize the need for consistent and comprehensive implementation of patient and family-centered care core concepts. Nurses need to understand that provision of ongoing support after a child dies minimizes parents’ feelings of abandonment and thereby decreases additional suffering. Nurses need to understand that complete delegation of care for bereaved parents to interdisciplinary partners is not best nursing practice. Nurses must not relinquish ownership of their

practice for this most vulnerable population. Nurses need to be taught how to provide high quality care for bereaved parents throughout their life and need to be supported in their efforts to do so. All of this begins with a better understanding of the meaning of the lived experience of parental bereavement. For as Cody (2000) states “the way a nurse understands a phenomenon invariably changes the way the nurse interacts with the person experiencing it” (p. 89). The very same could be said of all health care providers.

Education for other health care providers. All members of the health care team need to be better informed about the nature of parental bereavement. Health care providers across disciplines report feeling inexperienced in their communication skills with children and their families about matters concerning end of life care (Contro, Larson, Scofield, Sourkes, & Cohen, 2004). Education to advance providers’ knowledge, skills, and attitudes can empower the health care team as a whole to provide better care for bereaved parents in the future. All health care providers across disciplines and settings would benefit from a deeper understanding about the lived experience of parental bereavement, how grief and bereavement differ conceptually, how behaviors and care processes minimize or add to parents’ suffering, how important it is to uphold patient and family-centered care excellence, and how important their ongoing support is to bereaved parents along their lifelong journey towards healing.

Education for communities. The general public would greatly benefit from education. With a better understanding of the nature of parental bereavement, family, friends, work colleagues, acquaintances, and even strangers would be in a better position to support bereaved parents along their journey toward healing. To be supportive, they need to better understand what it means to be a bereaved parent. Community education, amongst many things, should include what to say and what not to say to a bereaved parent, as well as what behaviors can minimize or increase the intensity of parents' suffering.

Practice. The rich description of parents' lived experience will arm nurses with a greater understanding of the nature of parental bereavement, enabling them to decide if findings are transferable to their practice. A deeper understanding of parents' experiences could inform clinical practice guidelines. A clinical practice guideline which addresses parents' lived experience of parental bereavement would support nurses in meeting standard PPC-PFC 2 of the National Hospice and Palliative Care Organization's (NHPCO) Standards for Practice for Pediatric Palliative Care and Hospice which states: "Comprehensive anticipatory loss, grief and bereavement support methodologies are offered as an integral component of care to the child and all family members from diagnosis or at admission into the program" (NHPCO, 2009, p. 11). A clinical practice guideline might describe the structure of the lived experience of parental bereavement, include general recommendations that minimize additional

suffering and maximize support along the parent's journey towards healing, and inform provision of anticipatory guidance.

Nurses should strive to maximize behaviors and care processes that minimize additional suffering, while eliminating those which intensify parents' suffering. For example, nurses should strive to consistently incorporate patient and family-centered care practices when caring for children with cancer and their families. Cancer, a chronic illness, is curable in many instances; however, children still die of the disease. Implementation of patient and family-centered care is not only important during a child's illness but also has the potential to minimize additional, long-term parental distress in the event the child should die.

Nurses ought to consider the extent to which they support bereaved parents after a child has died. While there may be a natural tendency for pediatric nurses who once cared for the child during illness to separate themselves from the child's parents over time, findings suggest that many parents feel supported by ongoing, periodic communication with their child's nurses and other health care providers. Great opportunity exists for pediatric nurses to improve the nursing care of bereaved parents, with whom they likely have developed therapeutic, caring relationships.

In a very practical way, pediatric nurses might consider creative ways to organize a unit or service-line-based bereavement care program. A nurse-led program such as this could entail several components. Pediatric nurses might start by developing and maintaining an up-to-date database for the purposes of recording

important demographic information, such as the child, parent, and other family members' names; important dates, such as the child's birthday, diagnosis day, and deathday; the child's diagnosis; parents' contact information, including address and phone number; any specific religious, spiritual, or cultural beliefs; and anything else that was uniquely important to the child and family. Based on information contained in this database, pediatric nurses could then plan periodic communication with the child's parents as important dates draw near. For example, pediatric nurses could write a short note to the parents on their child's birthday simply to communicate that they are being thought of in a special way and that their child is being remembered. Pediatric nurses might consider calling the parents to speak with them on the telephone annually as their child's deathday approaches simply to inquire as to their wellbeing and to let them know that they are being remembered. Pediatric nurses might also gather appropriate bereavement-related literature to send to the parents if they are interested in reading such material. Pediatric nurses should also be knowledgeable of community-based parental bereavement support groups which exist so that they can make appropriate referrals.

A bereavement care program such as this could also be adapted and implemented fairly easily by pediatric nurses who practice in school health. It would be important, of course, for pediatric nurses regardless of practice setting, to assess, in an ongoing manner, parents' wishes for continued written or telephone communication. It is possible that some parents may not wish to have continued

contact. However, many parents in this study indicated that they would not only be open to ongoing, periodic communication with their child's nurses but also would welcome it.

Pediatric nurses might also explore opportunities to facilitate or co-facilitate, with interdisciplinary partners, formal hospital-based parental bereavement support groups. Parents who experience the death of a young child due to cancer develop close relationships with their child's nurses, as well as with other parents with whom they share a common lived experience. Kelly, for one, would have found a hospital-based bereavement support group to be helpful. It would be beneficial if hospital-based parental bereavement support groups were offered on at least an annual basis, rather than discontinuing the group entirely after one or two years, or after some other arbitrary period of time. Facilitation of a hospital-based bereavement support group that meets on some ongoing basis is particularly important in light of the finding that parents report a significant decrease in support after the first two years in spite of an ever increasing need. Parents may or may not choose to attend annually, but if pediatric nurses were to at least extend the invitation it would demonstrate that they care about parents' well-being, remember them, and most importantly remember their child.

Parental bereavement support, whether provided on a one-to-one basis, in a community-based support group, or in a hospital-based support group should attend to the continued parenting relationship. A support group meeting might center on this

essential aspect of the parental bereavement experience. Parents could be given the opportunity to discuss the ways in which they continue their parenting relationship and the degree to which they find it to be helpful. For without attention to this essential aspect of the parental bereavement experience, nurses and other health care providers may unknowingly be omitting an area that can enhance the support they provide.

Continued support can minimize additional suffering. Since parental bereavement is a new state of being with no end, nurses must consider their role in supporting parents for the long term. This first begins with recognition of a parent's lived experience of parental bereavement. While pediatric nurses who provided direct care for the child and his or her parents may be in an optimal position to support bereaved parents, nurses who care for adult patients also have opportunity to support bereaved parents. However, nurses who practice in adult health may not even be aware that the patient for whom they care is a bereaved parent. Assessment of adults' loss history at all points of care across the lifespan could be beneficial for screening purposes. If adult nurses recognized that the patient for whom they care is a bereaved parent, they would be in a better position to ensure maximum supports are in place throughout a parent's lifetime.

Pediatric and adult nurses alike are also in a prime position to provide bereaved parents with anticipatory guidance. Sharing what is known about the lived experience of parental bereavement with bereaved parents can decrease a parent's feeling that they are isolated in their experience, demonstrate the normalcy of their experience,

and help them to navigate their new state of being in the presence of their child's absence. Joan recommends that a map be created to help parents navigate bereavement. While Joan relied on Jewish death and mourning customs to inform her of traditional death rituals that were to be done immediately after Joshua died, such as how to bury the dead, how to grieve, and what to do immediately after the death of a loved one, Joan had nothing to help her navigate the next 15 years of her life that she now lives. Joan wishes she had a map. Joan thinks a map, or ongoing plan, would be very helpful for bereaved parents (pg 78, lines 7-16, 18-23; pg 79, lines 1-4). Joan says this map would have to be very general, containing nothing too specific because parental bereavement is such a personal experience (pg 82, lines 15-17). However, Joan advises certain things must be included in this map, including: a) health care providers better preparing parents for the possibility of their child not surviving, while still actively treating the child's illness (pg 79, lines 10-23; pg 80, lines 1-16); b) ways for parents to feel more self-worthy after their child's death (pg 79, lines 8-10); and c) supportive people who can help parents implement the map be it by providing emotional, physical, or monetary support (pg 82, lines 13-21). Joan offers some excellent ideas which could be incorporated into a reference handbook to guide parents throughout their parental bereavement experience.

The need for such a reference for parents is immediate. In fact, beginning steps towards this end are underway. The American Childhood Cancer Organization (ACCO), the leading publisher of pediatric cancer resources for children with cancer

and their families, is publishing the first palliative care resource book for parents of children with cancer. As a direct result of this research study, ACCO has invited me to author a chapter covering the lived experience of parental bereavement, including grief. I am most honored to have been granted this opportunity to collaborate with ACCO on this important project through which I can translate research findings to help bereaved parents directly. Further, this resource could certainly be used by nurses in their own practice to assist them in providing anticipatory guidance and education for bereaved parents for whom they care.

As nurses strive to improve nursing care for bereaved parents, astute attention must be given to comprehensive documentation of that care which is provided. Opportunity to improve nursing documentation of bereavement care is evident in the literature. In a retrospective chart review of 145 pediatric cancer patients who died within a one year period at one children's hospital in the United States, Bradshaw, Hinds, Lensing, Gattuso, and Razzouk (2005) found no documented evidence of bereavement follow-up in half (50.3%) of the cases. It is unclear if bereavement care was in fact provided but just simply not documented or if bereavement care was not delivered altogether. As nurses strive for excellence in the delivery of nursing care for bereaved parents, documentation merits attention.

Nursing knowledge generated from this study will have significant impact on practice. Nurses will gain a deeper understanding of the meaning of the lived experience of parental bereavement. With greater understanding, nurses will be

empowered to advance the care of bereaved parents as they strive towards nursing care excellence.

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Chapter XII

APPENDICES

Appendix A

Informed Consent Form

The Lived Experience of Parental Bereavement

Informed Consent

1. Researcher's Affiliation

The researcher is Christine Denhup, a master's prepared nurse and a student in the Seton Hall University College of Nursing's Doctoral (PhD) Program. The researcher is doing a research study which may help nurses better understand and care for fathers and mothers who have experienced the death of a child.

2. Purpose and Duration

The aim of the study is to describe the lived experience of bereaved fathers and mothers who have experienced the death of a child due to cancer. Fathers and mothers whose child died of cancer are invited to share their experience with the researcher.

The researcher hopes to learn from fathers and mothers in order to help nurses provide better care for parents experiencing the death of a child in the future.

The researcher is asking fathers and mothers to participate in 1 to 3 interviews which will take about 1 to 2 hours each (a total of 1 to 6 hours) at a convenient time for the father/mother and the researcher. After interviews are complete, the researcher will ask the participant to review the written interpretation of the interview data to ensure that the researcher has accurately understood what the participant has said. At this time, the participant may request that the researcher delete something that he/she has said and/or make changes that will better reflect the intent of what he/she originally told the researcher. This final review may take about another 1 to 2 hours of time.

3. Procedure

The researcher would like to talk with fathers and mothers who had a child, between 0 to 18 years of age, die due to cancer at least one year prior to the study. The father/mother will participate in 1 to 3 private interviews with the researcher. The father/mother may decide he/she wishes to talk with the researcher individually or he/she may decide to talk with the researcher together as the parents of a child. The interview will take place at a mutually convenient time and location. For

example, the participant and researcher might meet at the bereavement support group's meeting location, at the participant's home, or at another location of the participant's choice. The participant may also decide if he/she would like to talk with the researcher over the telephone, rather than meeting with the researcher in person for the interview.

In the interview, the researcher will ask the participant to tell the researcher what it has been like for him/her since his/her child died. The participant is free to tell the researcher anything he/she would like to about his/her experience. The researcher may make comments, such as "Go on", or "Please say more about what it was like for you", or "Can you think of anything else that would help me to understand what it has been like for you since your child died?" The researcher may ask the participant questions just to clarify what he/she says so that the researcher is sure to understand what the participant is saying. If the participant does not wish to answer any questions during the interview, he/she may say so and the researcher will move the discussion along. If at any time the participant feels uncomfortable or upset and does not wish to continue, he/she should please tell the researcher and the interview will stop. The participant can decide if he/she wishes to reschedule the interview for another day and time, or the participant can choose to stop participating in the study entirely.

The researcher will ask for the participant's written permission to tape-record the interview. The information recorded is confidential and the participant will be identified only by a pseudonym (made-up name). No one else except the researcher will have access to the information on the audio-tapes. The audio-tapes will be kept in a locked cabinet and no one else except the researcher will have the key to the locked cabinet. After the interview, the researcher will transcribe the audio-tapes and the audio-tapes will be destroyed after the study is completed.

4. Instruments

No questionnaires or survey instruments will be used in this research study.

5. Voluntary Nature

The father/mother does not have to agree to participate in this research study. Whether the father/mother chooses to participate or not, the services that he/she and his/her family receive at the bereavement support group will not change. The researcher knows that the decision to participate may be especially hard for fathers and mothers because it involves talking about their child and their child's death. The father/mother can ask as many questions as he/she would like to about the study and the researcher will take the time to answer them before the father/mother makes his/her decision. The father/mother does not have to decide today. The father/mother can think about it and contact the researcher later when he/she makes a decision. The researcher's contact information is provided below (see #14 Contact Information). If the father/mother agrees to participate he/she can change his/her mind. The father/mother can withdraw from the study at any time.

6. Anonymity

The participant's identity will remain be anonymous to everyone except the researcher. The participant will be identified only by a pseudonym (made-up name) and not his/her real name. The pseudonym (made up name) will be known only to the researcher so that no one will ever be able to link the information to the participant.

7. Confidentiality

The information that the researcher collects from this study will be kept confidential. Information that the participant shares with the researcher will be put away and no one but the researcher will be able to see it. The tapes from the tape-recorded interviews will be in a locked cabinet. Any information about the participant will have pseudonym (made-up name) instead of his/her real name. Only the researcher will know what the pseudonym (made-up name) is and the researcher will lock that information up with a lock and key. It will not be shared with or given to anyone. At the end of the study, the researcher will be sharing what she has learned with the participant. The participant will be given the chance to review the researcher's written report and verify the accuracy. Nothing that the participant tells the researcher will be attributed to him/her by name. Confidential information will remain confidential. The researcher's written report will be shared with her research committee at the College of Nursing, Seton Hall University without providing any identifying information about the father/mother. The researcher will also publish the study's findings in professional nursing journals and present the study's findings at professional nursing conferences, without providing any identifying information about the participant, in order that other nurses and health care providers may learn how to better care for mothers and fathers who experience the death of a child in the future.

8. Confidentiality of Records

The researcher will transcribe the tape-recorded interviews and store them on a secure USB memory key, not a computer hard drive, and the USB memory key will be kept in a locked, secured cabinet.

9. Risks or Discomforts

The participant may feel uncomfortable or upset when talking about his/her child and his/her child's death. The participant does not have to answer any specific questions, or take part in the interview if he/she does not want to. The participant does not have to give the researcher any reason for not responding to any question, or for wanting to stop taking part in the interview at any time. Should the participant become upset during the interview and wish to stop, the interview can stop for a period of time and then resume or the interview can end immediately.

In the event the interviews cause psychological distress and the participant would like to seek support, psychological counseling can be obtained from the following counselors/counseling centers:

- Kathleen Mercer, LCSW, Therapist – Manchester, CT (860) 568-4949
- Michele Binezewski, LPC, NCC, Counselor/Therapist – Glastonbury, CT (860) 462-3083
- Thomas Carlson, PsyD, Psychologist – Glastonbury, CT (860) 782-0922
- James Cont, PhD, LMFT, Psychologist – Glastonbury, CT (860) 484-3916
- Steven Zimbel, LCSW, Therapist – Glastonbury, CT (860) 375-5503
- Len Wysocki, MA, PhD, Psychologist – Marlborough & Glastonbury, CT (860) 308-1592
- Pamela Lubin McGuire, MSW, LCSW, Therapist – Vernon, CT (860) 598-0983
- Christine Routhier, LCSW, Therapist – Vernon, CT (860) 261-2151
- Heath Hightower, MSW, LCSW, Psychotherapist – Windsor, CT (860) 204-2051
- Norrette Lohr-Thierry, PhD, LMFT, Therapist – South Windsor, CT (860) 541-9630 ext. 7
- Jessica Assard-Wu, LMFT, Psychotherapist – West Hartford, CT (860) 521-8888
- Eileen Steker, LPC, Psychotherapist – West Hartford, CT (860) 313-4448
- Center for Serenity, Mental Health Care and Counseling – West Hartford, CT (860) 561-2343
- Jewish Family Services of Greater Hartford – West Hartford, CT (860) 236-1927
- Hartford Behavioral Health Cole Treatment Center – Hartford, CT (860) 548-0101
- John Ringwald, PhD, Psychologist – Middletown, CT (860) 347-6001
- Light Beyond Loss Bereavement Counseling – Canton, CT (860) 693-6847

10. Benefits

The participant may find it helpful to have the chance to talk about his/her child and tell his/her story and his/her child's story. While there are no other direct benefits to the participant, his/her participation may help other parents who are experiencing bereavement after the death of a child.

11. Reimbursements

The participant will not be provided with any payment to take part in this research study.

12. Compensation

The participant will not receive any compensation for taking part in this research study.

13. Alternative Procedures

Not applicable.

14. Contact Information

If the participant has any questions he/she may ask them now or later, even after the study has started. Listed below is the list of whom to contact:

- a) The father/mother may contact the Principle Researcher directly: Christine Denhup, MSN, APRN Telephone: (203) 257-6202; Address: Seton Hall University, College of Nursing, 400 South Orange Ave., South Orange, New Jersey 07079.
- b) If the father/mother has questions about the study process, he/she may contact the researcher's Faculty Advisor: Judith Lothian, PhD, RN Telephone: (973) 761-9273; Address: Seton Hall University, College of Nursing, 400 South Orange Ave., South Orange, New Jersey 07079.
- c) If the father/mother has questions about his/her rights as a study participant, please contact Seton Hall University's Institutional Research Board (a committee whose task it is to make sure that research participants are protected from harm)
Telephone: (973) 313-6314; Address: Seton Hall University, IRB Presidents Hall Rm. 325, 400 South Orange Ave., South Orange, New Jersey 07079.

15. Permission for Audio-tapes

The researcher is asking for the participant's written permission to tape-record the interview. The information recorded is confidential and the participant will be identified only by a pseudonym (made-up name). No one else except the researcher will have access to the information on the audiotapes. The audiotapes will be kept in a locked cabinet and no one else except the researcher will have the key to the locked cabinet. After the interview, the researcher will listen to and transcribe the audiotapes. The audiotapes will be kept for at least 3 years after the study is completed.

16. Participant given a copy of the Informed Consent Form

The researcher will give the participant a copy of his/her signed and dated Informed Consent Form.

Consent to participate is indicated by returning the signed and dated Informed Consent Form to the researcher.

Participant's Signature

Date

Appendix B

Flyer

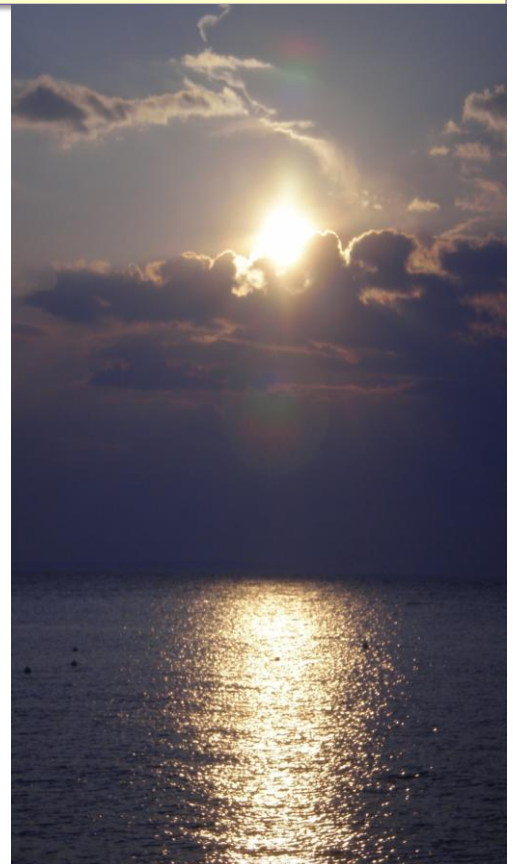
Parents, would you like to share your story?

My name is Chris Denhup. I am a master's prepared nurse. I am studying what it is like for parents after their child dies. I would like to talk with you and learn from you so that I can help nurses to provide better care for mothers and fathers after the death of a child in the future.

If your child died from cancer at least 1 year ago and was between 0-18 years at the time of his or her death, please contact me by e-mail or telephone if you would like to learn more about volunteering to be part of this study.

I look forward to speaking with you.

Thank you,
Chris Denhup, APRN, Doctoral Nursing Student
College of Nursing, Seton Hall University
Email: christine.denhup@student.shu.edu
Telephone: (203) 257-6202



Appendix C

Say Their Names, by Don Hackett

“The time for concern is over. No longer are we asked how are we doing. Never are the names of our children mentioned to us. A curtain descends. The moment has passed. Lives slip from frequent recall. There are exceptions: close and compassionate friends, sensitive and loving family. For most, the drama is over. The spotlight is off. Applause is silent. But for us, the play will never end. The effect on us is timeless. Say their names to us. On the stage of our lives they have been both lead and supporting actors and actresses. Do not tiptoe around one of the greatest events of our lives. Love does not die. Their names are written on our lives. The sounds of their voices replay within our minds. You feel they are dead. We feel they are of the dead and still live. They ghostwalk our soul, beckoning in future welcome. You say they were our children. We say they are. Say their names to us and say their names again. It hurts to bury their memory in silence. What they were in flesh is no longer with us. What they are in spirits stirs within us always. They are of the past, but they are a part of our now. They are our hope for the future. You say not to remind us. How little you understand we cannot forget. We would not if we could. We understand you, but feel pain in being forced to do so. We forgive you, because you cannot know. And, we would forgive you anyway. We accept how you see us, but understand that you see us not at all. We strive not to judge you, for yesterday we were like you. We love you, will make no exceptions toward you. But we wish you

could understand that we dwell both in flesh and in spirit. The mystery is that you do, too, but know it not. We do not ask you to walk this road. The ascent is steep and the burden heavy. We walk it not by choice. We would rather walk with them in flesh, looking not to spirit roads beyond. We are what we have to be. What we have lost, you cannot feel. What we have gained, you cannot see. And, we would not have you. Say their names, for they are alive in us. They and we will meet again, though in many ways we've never parted. They and their lives play light songs on our minds, sunrises and sunsets on our dreams. They are real and in shadow, were and are. So, say their names to us and say their names again. They are our children, and we love them as we always did. Say Their Names!

Retrieved from <http://tcfbluegrass.org/saytheirnames.html>.

Appendix D

Precious Child, by Karen Taylor-Good

In my dreams, you are alive and well
Precious child, precious child
In my mind, I see you clear as a bell
Precious child, precious child
In my soul, there is a hole
That can never be filled
But in my heart, there is hope
'Cause you are with me still

In my heart, you live on
Always there never gone
Precious child, you left too soon
Tho' it may be true that we're apart
You will live forever... in my heart

In my plans, I was the first to leave
Precious child, precious child
But in this world, I was left here to grieve
Precious child, my precious child

In my soul, there is a hole
That can never be filled
But in my heart there is hope
And you are with me still

In my heart you live on
Always there, never gone
Precious child, you left too soon,
Tho' it may be true that we're apart
You will live forever... in my heart

God knows I want to hold you,
See you, touch you
And maybe there's a heaven
And someday I will again
Please know you are not forgotten until then

In my heart you live on
Always there never gone
Precious child, you left too soon
Tho' it may be true that we're apart
You will live forever... in my heart

Retrieved from

http://www.lyricsmode.com/lyrics/k/karen_taylor_good/precious_child.html.